

# **Unravelling the Fertility Industry: Challenges and Strategies for Movement Building**

**International Consultation on Commercial, Economic and  
Ethical Aspects of Assisted Reproductive Technologies**

**January 22 - 24, 2010, New Delhi**

**A Report**

**Sama - Resource Group for Women and Health**

12104  
CLIC-  
CHC

**SOCHARA**  
**Community Health**  
**Library and Information Centre (CLIC)**  
Community Health Cell  
85/2, 1st Main, Maruthi Nagar,  
Madiwala, Bengaluru - 560 068.  
Tel : 080 - 25531518  
email : clic@sochara.org / chc@sochara.org  
www.sochara.org



# Unraveling the Fertility Industry: Challenges and Strategies for Movement Building

*International Consultation on Commercial, Economic and Ethical Aspects of  
Assisted Reproductive Technologies (ARTs)*

## A Report

22- 24 January 2010, New Delhi

*Organised by*

**Sama – Resource Group for Women and Health, New Delhi**

94  
11/6/2014  
Library

The information provided in this report is for wider dissemination, and may be used by anyone with due acknowledgement to Sama.

First published in 2010

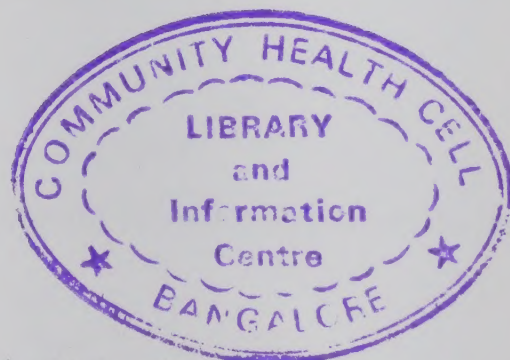
*Published by:*

Sama- Resource Group for Women and Health  
B-45, 2nd Floor,  
Main Road Shivalik, Malviya Nagar  
New Delhi- 110017  
Ph. No.: 011-65637632, 26692730  
E-mail: sama.womenshealth@gmail.com

Cover : Sarojini N

*Printed by:*

Impulsive Creations  
8455, Sector C, Pocket 8,  
Vasant Kunj  
New Delhi-110070



WH-105  
12704 p10



# Contents

---

## *Acknowledgements*

### **DAY 1**

The Consultation in Perspective	1
The Gene Express: Speeding Toward What Future?	4
Biogenetic Transactions: Politics and Economics	8
Global Experiences: Asia Pacific	21
Global Experiences: South Asia	30
Emerging Perspectives and Challenges: Towards a Global Movement	41

### **DAY 2**

Global Experiences: South Asia	44
Global Experiences: Middle East	56
Global Experiences: US, Canada and the Netherlands	67
Emerging Perspectives and Challenges	77

### **DAY 3**

Global Experiences: Latin America	80
In Pursuit of Tissues: Global Movement and the Biogenetic Form	94
Challenges and Strategies: Where do we go from here?	100

The Way Forward	106
-----------------	-----

*Programme*

*About Sama*

*Speakers' and coordinators' profiles*

*Participants*

## Acknowledgements

---

Sama would like to acknowledge the invaluable contributions of the following towards this consultation: Dr Aditya Bharadwaj, Dr Amit Sengupta, Dr Betsy Hartmann, Dr Manjeer Mukherjee, Dr Mohan Rao, Dr Padmini Swaminathan, Pramada Menon, Sarah Sexton and NB Sarojini.

We are grateful to the speakers and coordinators of the consultation: Dr Aditya Bharadwaj, Dr Amar Jesani, Dr Amit Sengupta, Dr Betsy Hartmann, Chayanika Shah, Dr Elizabeth Roberts, Farida Akhter, Hedva Eyal, Dr Imrana Qadeer, Judy Norsigian, Dr Jyotsna Agnihotri Gupta, Dr Lakshmi Lingam, Dr Malini Bhattacharya, Manisha Gupte, Dr Marcia Inhorn, Dr Marcy Darnovsky, Dr Marilena Correa, Dr Mohan Rao, Dr Nighat Khan, Dr Padmini Swaminathan, Pinky Singh Rana, Pramada Menon, Dr Renate Klein, Renu Khanna, Sandhya Srinivasan, Dr Sarah Hodges, Sarah Sexton, NB Sarojini, Dr Shree Mulay and Dr Young-Gyung Paik.

We deeply appreciate the active engagement of all consultation participants, who brought rich detail and debate to the discussions.

We would like to acknowledge IDRC, HIVOS, students of the class on 'Critical Issues in International Women's Health' at Stanford University and other individuals who have supported the consultation financially. We particularly thank Dr. Navsharan Singh from IDRC, who has been a constant source of support and encouragement.

We thank Rukmini Datta for documenting the proceedings of the consultation, together with inputs from Vrinda Marwah, Sarojini, Pramada and Anjali Sheno.

We are grateful to our volunteers; Swati, Sakshi, Chandana and Priya. We thank Ritwik and Ranjan De for putting together the photographs used in this document, and Pakhi for the artwork.

And finally, a special mention for the Sama team; Deepa, Beenu, Susheela, Aastha, Preeti, Anjali, Svetha, Bhawna, Ashok, Antony, Renuka, Vrinda and Sarojini.



# The Consultation in Perspective

Anjali Sheno, Aastha Sharma and Pramada Menon

Sama's engagement with issues of women and health evolved in the context of the women's movement, people's health movement and other democratic rights movements, which link concerns of women's health with larger social determinants. The organisation's long standing engagement with women's health and rights especially in the realm of coercive population policies, hazardous contraceptive technologies and the medicalisation of women's bodies has led to the understanding that *conceptive* and *contraceptive* technologies lie on the same continuum. These technologies target women's bodies by intervening in and altering their physiological processes. Moreover, they raise a number of complex issues that emerge from the links between health, society and technology.

Within this context, it is important to give voice to women's own experiences and their perceptions of fertility, infertility, and to place women's decisions within the context of their family dynamics and their social realities. It is with this approach that Sama has been addressing the concerns around Assisted Reproductive Technologies (ARTs) through various strategies including action research, advocacy and information sharing.

While the preliminary research, initiated in 2004, revealed the unregulated practices of ART clinics and the implications of these technologies on women and couples, the current study is exploring the commercial

aspects, unchecked proliferation of clinics, penetration of these technologies into smaller towns and cities and the underlying caste-class dimensions. Sama has also been actively engaging with government bodies and policy makers with regard to the regulatory aspect of these technologies in India; voicing its concerns on related issues like the ICMR's (Indian Council of Medical Research) National Guidelines for Accreditation, Supervision and Regulation of ART clinics in India, the proposed Draft Assisted Reproductive Technologies (Regulation) Bill and Rules and advocating for a comprehensive legislation.

Sama has been creating platforms for collective debate, discussion and evolving strategies around these issues through consultations and workshops, both at the community and policy levels. Sama has, through these, attempted to draw inter-linkages between ARTs and issues like patriarchy, public health, nutrition, and social determinants of health. In addition, Sama's previous consultations have also focused on unraveling the growth and proliferation of ARTs in the context of India. In this endeavour, inter-linkages were made with other movements and networks working on issues of health, women's rights, sexual rights, disability rights, child rights, law, and bioethics, among others.

This consultation's focus on the commercial, economic and ethical aspects of ARTs was a



logical step ahead to understand the global discourse. In a time when tissues, gametes, technologies, as well as the people who seek these technologies, are crossing borders, this issue has gone beyond national or even regional boundaries.

This consultation aimed to bring together a balanced representation of activists, scholars and researchers from different movements, networks, and organisations from across the world working on similar concerns.

### **Context of Assisted Reproductive Technologies**

Assisted reproductive procedures are more than mere technology. They have deep roots in the existing social arrangements and power relations and it is in this social context that their development, practice and propagation prevail. The premium placed on motherhood and biological progeny, and the social stigma associated with infertility, are largely responsible for the escalation of birth technologies into a fertility industry. Today, we are witnessing the globalisation of reproductive process, labour and tissues by cross border sourcing of reproductive labour through surrogacy and egg donation, medical tourism, which has facilitated the commercialisation and commodification of women's bodies and reproductive tissues. With the booming reproduction market, the consequent exploitation of women is a reality in all aspects of their lives. In many countries like India, such practices gain legitimacy by virtue of a non-existent regulation; resulting in unethical practices by ART clinics and research centres. With newer aspects of technology like embryonic stem cell research and cloning being rolled out, the law is lagging far behind.

It was earlier believed that such technology was only going to be accessed by the rich, but it is now seen that investing vast sums of

money to have a child cuts across all classes. What is also clear, in the case of egg donation and surrogacy, is that it is the poorer and more vulnerable who often become targets of such technology.

Sama has attempted to bring into the ART discourse perspectives from a range of movements – women's, health, disability rights, sexual rights and child rights. Some of the issues of concern that have emerged from this synthesis are:

- How can we protect women's health and rights in a time when oocytes are an important research 'raw material'? Global economic disparities, unregulated cross border trade in human biogenetic material (like aborted female fetuses) and unregulated practices in ART clinics in some countries have led to unethical, uninformed sourcing of embryos and oocytes.
- Can surrogacy be considered a form of livelihood or is it becoming a temporary survival strategy for some economically vulnerable women in countries like India? If it is the 'noble deed' that it is believed to be, why does it continue to be stigmatised and carried out in secrecy, with women even leaving their houses and families for nine months?
- With varying laws across countries regarding citizenship and nationality, how do we decide on the nationality of the child born to a surrogate? For instance, in a recent case, twins of a German couple born to a surrogate in India have been refused citizenship by both the countries.
- Do ARTs reinforce heteronormativity, or do they de-link reproduction from sexuality, marriage and heterosexuality and actually make biological parenthood an option for



LGBTQIs (Lesbian, Gay, Bisexual, Transgender, Queer and Intersex)? The current screening criteria do not make these technologies available to LGBTQIs. Further, how can we ensure that ARTs are not abused for sex selection, or to create only 'able-bodied' babies with 'desirable' gender and physical traits?

## **Objectives of the Consultation**

The consultation expected to: discuss how ARTs are interacting with poverty, business and commerce, religion, patriarchy and caste in various contexts around the globe; unravel the process through which the proliferation, standardisation and routinisation of ARTs is taking the shape of an industry; learn from the experiences of regions where these technologies are more advanced, and anticipate the trends to come in countries where these technologies are catching up; know what strategies have been developed by activists and groups working on these concerns and their challenges and outcomes; understand the differential perspectives of governments towards ARTs across the globe, the roles assumed by them in dealing with these technologies, and the underlying reasons for these. It sought to bring into focus concerns from a public health perspective, addressing the underlying causes of infertility and the arguments of occupational patterns, environmental changes, lifestyle changes that have negatively affected fertility levels and

created conditions for people to undergo these technologies.

At the end of the consultation, the following specific outcomes were sought to be achieved:

- Information exchange from activism, research, practices, policies and regulatory mechanisms gathered from across the world;
- Culling out of strategies from various countries and examining whether they can be used trans-nationally;
- Building collaborations and networks as an effort towards movement building around new reproductive and genetic technologies, while being aware of allies and collaborators in the effort towards garnering health rights;
- Comprehension of the advancements and debates around scientific research on infertility care, stem cells and cloning, and examining the research priorities in the context of access to basic health care; and
- Mapping how different kinds of 'infrastructure', agencies and agents facilitate the movement of technologies and results of research; the movement of those in search of such facilities, and those willing to 'host' them.



## Key Note Address

# The Gene Express: Speeding Toward What Future?

Betsy Hartmann

Developments in genetic research and Assisted Reproductive Technologies are occurring with great speed, not just technologically but also in terms of the growth of new markets, in a world where the compression of time and space is a hallmark of capitalist globalisation. This speed poses a political challenge to us. To be able to build a movement that takes on ARTs in all of its complexity, there is a need to slow down and think together about certain thematic clusters.

First are the broader contours of geneticisation of which ARTs are one dimension, but not the only one. First coined by Abby Lippman, 'geneticisation' is the process by which genetics increasingly has come to explain not only health and disease but to normalise and naturalise social differences as biologically based. The 'genetic code', a term originally derived from computer science, has now burgeoned into a full-blown genetic discourse that shapes the knowledge and experiences of our bodies and the world, whether we like it or not. Geneticisation is more than eugenics, and it manifests differently depending on whether you are rich or poor, young or old, black or white, man or woman, gay or straight, from the global North or from the global South. It is double-edged, providing rewards as well as punishments, posing risks at the same time as it purports to minimise them. For instance, the DNA test that frees the wrongly convicted

prisoner is simultaneously a tool of authoritarian surveillance; just as so-called individual choice becomes individual burden when the pregnant woman is told she is carrying a disabled foetus; hopes of cures are dashed against the rocks of exorbitant expense, bad science and false pharmaceutical claims.

Geneticisation is at once reductionist and expansive. It reduces us to smaller and smaller parts of ourselves at the same time as those parts acquire value and enter national and global economic circuits. Women's bodies in particular have become a kind of genetic capital for biotech research and reproductive technologies. We are no longer whole, but are instead, the sum of our parts.

It is important to look not only at what geneticisation includes, but what it excludes: the structural violence of poverty, discrimination, toxic environments and lack of access to health care that produces the most widespread and serious risks of sickness and death. Additionally, there are health risks of ARTs themselves – the impact on women's bodies of egg harvesting, surrogacy, multiple births. We need an affirmation of the right to reclaim the meaning of risk, including the right to determine what information and knowledge are used to define it.

The second thematic cluster is that of the market, or rather markets. There is a need to understand very concretely how ARTs



and related markets work, in order for any endeavour to be politically effective. It is not enough to just repeat the mantra of neo-liberalism; it is essential to consider the diversity of markets and the extent of state support and facilitation of them in countries such as India, China, South Korea, Singapore, the UK, Israel, the Czech Republic, and so on.

Some of the key issues that come up around markets are:

- The connection between the fertility industry and scientific research, for example, how spare eggs, embryos, aborted fetuses, placentae, umbilical cords and other tissues from the former supply the latter.
- The transition of ARTs from a niche luxury market to a larger, if not mass market.
- The relationship between reproductive tourism and medical tourism – and even old-fashioned tourism. For example, egg ‘donors’ are being wooed to India with promises of exciting tours afterwards – ‘give your eggs and then go to the Taj Mahal’.
- The way gestational surrogacy, in separating the components of conception, helps to create a larger market for each, and how Pre-implantation Genetic Diagnosis (PGD) has expanded the market beyond infertile couples.
- The transformation of ethics and informed consent from principles into marketable commodities, and similarly how ‘donation’ is deployed to mask market transactions and to turn gifts of blood and body parts into private property.
- The role of advertising in boosting both supply and demand, the role of media in normalising through sensationalising

ARTs, and the ideological impact of both in terms of feeding market speculation.

- The politics of regulation, one of the trickiest issues, wherein some liberals argue that what is needed is clearer establishment of property rights in order to regulate the ART market. Are body parts now the latest enclosure of the commons? What kind of regulation do we want, can we get, should we demand?

A third cluster of issues relates to science. The corporatisation of scientific research in the last decades, as well as the increasingly porous borders between public finance and private gain play out in the ART field. In the US, for example, due to changes in the law, universities and non-profit institutes can now patent federally funded research results. More than ever before, the profit motive is helping to push the direction of research towards commercial applications. One question to consider is: how can progressive feminist epistemologies and interventions reshape the nature of genetic research itself, from the framing of questions down to laboratory experiments? There is a need to be bold and scientifically literate enough to assess what role genetic research might play within a progressive, feminist health framework.

Last, but hardly the least, are the intersections between gender, sexuality, race, class, disability, nationality and ARTs. There are many obvious hierarchies and dichotomies as well as less obvious ones. For instance, while white women’s reproduction continues to be valued and black women’s discouraged (fertility treatments for white women, population control for black women), Dorothy Roberts reminds us that the ART market is now expanding in the US to target more women of colour, particularly for PGD. In addition, race as a genetic category is being mobilised by the pharmaceutical industry in

order to obtain patent protection and drug approval.

In the case of gestational surrogacy in India, hierarchies of gender, race, caste, class, religion, ethnicity and nationality are startlingly clear: at the apex, well-off couples from abroad and rich Indian clinic directors (although those couples too can be exploited by an industry based on patriarchal values and false hopes); in the middle, medical personnel and surrogate brokers; and at the bottom, poor women serving as rentable wombs.

Poor women are definitely exploited, receiving a small fraction of the fee, but that fraction represents a considerable sum of money to buy a house or business, send a child to school, or pay for a family member's medical operation. Exploitation and opportunity are wound and bound up in one.

In terms of selection for disability, much has been written about the problematic context in which women are making the 'choice' to abort a disabled foetus or in the case of In Vitro Fertilisation (IVF), to screen out embryos that carry the risk of future disability or chronic disease. However, there is a need to look at the results of this process further down the line. For example, disability rights activists in the US point to how the population of people with Down's syndrome is now shrinking, leading to more isolation and lack of community. Meanwhile, the search for genetic cures for conditions such as autism takes attention and resources away from desperately needed support services for autistic people and their families. As the neoliberal safety net shrinks, class privilege comes to determine even more than before who can afford services and who cannot.

As for sexuality, ARTs have allowed lesbian and gay couples to have biologically related children and make families, and thus has been hailed by many as disrupting gendered

reproductive norms. Yet, the notion of the biological middle class nuclear family actually gets reinforced in the process. Further, is the focus on ARTs taking attention away from the need to fight for the rights of lesbian, gay, bisexual, intersexual, and transsexual people to adopt?

Scholars such as Rose and Novas argue that the nature of citizenship itself is changing: geneticisation is producing a new bio-citizen who has the responsibility to manage health risks and live life through acts of calculation and choice. What does this do to those who have not achieved full citizenship in the traditional sense? What is the relationship between the bio-citizen and the non-citizen? Are there parallels between the immigrant who gets put on the fast track toward US citizenship if he or she joins the army and the Latina immigrant who gets a green card because she is willing to serve as a surrogate? The women in Anand, Gujarat are literally producing citizens of other countries, while they remain second or third class citizens in their own, subject to a state-imposed two child norm when it comes to their own offspring.

It is critical to remain attentive to how the health and psychological burdens of ARTs are profoundly gendered, falling mainly on women, while so much of the language used to analyse them is not. Concepts like bio-citizenship, for example, are useful tools, but if we are not careful, they can obscure rather than illuminate gender inequalities. Gender must be central - as are the other intersections with sexuality, race, class, nationality and disability - if we are to move our politics as well as the theoretical dimensions of the ART debate forward.

Some political dilemmas that need to be confronted are:

The issue of abortion rights (especially in the US) around disability is a minefield, but so is the question of whether or not strategic alliances should be made with anti-abortion



groups opposed to the egg trade and other ARTs. A similar issue came up around population control when anti-abortion activists actively sought to make common cause around sterilisation abuse.

Second is the question of how we view poor women being hired as gestational surrogates. Clearly, they are performing a type of reproductive labor, so we do support them to get better work conditions and fairer remuneration? There are some of the same fault lines here as in the 'support sex workers' rights' vs. 'end prostitution' debate.

Third regards whether or not to ban certain reproductive and genetic technologies. Will a ban drive them further underground and

criminalise the most vulnerable people? Here there is a parallel with the controversy over whether to ban the use of ultrasound technologies used in sex selection.

Common commitments to end patriarchy, ensure health care for everyone, and work for social, economic and environmental justice in all their many forms must be affirmed. While keeping one eye on ARTs, we need to keep the other on the broader political agenda that challenges the very idea of geneticisation as the key to progress. We must resist the individuality and nano-partitioning that geneticisation pushes on us, with an alternative vision of community and collectivity in which all of us are citizens and all of us are whole.

# Biogenetic Transactions: Politics and Economics

Coordinators: Manisha Gupte and Judy Norsigian

## Technology, Markets and the Commoditisation of Life

*Amit Sengupta*

The fertility industry today is a multi-million dollar, global business. Various means have been used to try and present ARTs as designed to address the 'needs' of people, particularly women. However, ARTs remain a business enterprise despite the hard work that goes into trying to make it appear like social service. Though large parts of the entire health care industry are businesses too, the difference between the ART industry and other health services is that the former is all about finally arriving at a 'product' – the baby.

As in any good business, there are many components that are required to come together for its functioning: sperm, ovum and the receptacle (womb). Fertility clinics, as the seat of this business enterprise, bring these components together. They ensure that technology matches needs, that services are marketed and that there is collaboration between players like doctors, hospitals and 'patients', among others. Thus, fertility clinics form the apex of this pyramid, referring patients from smaller clinics to those offering sophisticated technology in bigger cities.

As in other businesses, clinics use well thought-out advertising, appealing to potential 'patients' and leveraging on hope:

*'All Muslim couples will be counseled regarding the proscription of their religion while selecting an appropriate treatment modality. We will ensure that none of the Shariat laws are broken while providing infertility treatment'*

*'In all things it is better to hope than to despair – every woman can become a mother'*

*'Dream comes true.... because every couple has a right to have their own child'*

In the US alone, trade in human eggs is an annual business of US \$ 38 million. Just like in any other business, the quality of sperms and eggs matters and there are egg brokers who ensure a certain quality of eggs by maintaining a large and increasing pool of egg donors, many of them college students who have been profiled for quality. Sperm banks have been known to specify the requisite height, colour and other traits of donors; have asked for medical information of both sides of their families and evidence of the absence of any chronic health problems.

However, given the high cost of hiring a womb (or a surrogate mother) in the developed North, the business of hiring wombs has started crossing borders, giving rise to the phenomenon of 'wombs sans frontiers'. In a globalised world, this movement across borders to find wombs that can be the receptacles of the sperm and the ovum makes for reproductive tourism,



an extension of 'medical tourism'. There are two major drivers of the growing industry of reproductive tourism: variation in laws on ART regulation, and wide variation in costs. For both these reasons, India, Thailand and China are popular international destinations for ARTs. For instance, the approximate cost of surrogacy in India is Rs 1 million (Rs 45 equals 1 USD) compared to Rs 2.5-3.5 million in the US. Overall, Indian clinics report that the incidence of surrogacy has more than doubled in the past three years taking it to an estimated national business size of US \$ 445 million.

These technologies are backed by powerful interests and have now moved beyond the domain of a few big doctors, as was the case 30 years back. Large corporations and pharmaceutical companies are creating the myth of infertility as a disease which can be treated with drugs. More and more people are being brought into the new and broadening definition of infertility. Service providers are encouraged to shift to new drugs, influenced by aggressive promotion. Companies manufacturing equipment for ARTs also have a large stake in the fertility market.

The research industry too has a high stake in this business. Most researchers who are working to produce human embryonic stem cells use embryos that were created, but not used, during IVF procedures. Similarly, eggs 'donated' for an entirely different purpose are being used for research, thus raising a plethora of ethical issues.

One of the powerful drivers of the fertility industry is biology. No living species on earth can boast of a cent percent fertility record, so there will always be a pool of people who are infertile. For instance, about 2000 years ago, the Charaka Samhita talked about infertility. This is compounded by the atavistic need felt by humans to procreate and produce someone

like oneself, encouraged also by literature, mythology and folklore. Till about 30 years back, there was nothing by way of infertility treatment that the industry had to offer. But this changed in 1978 with the first in-vitro fertilisation, and the huge pool of infertile men and women became candidates for inclusion in the market for ARTs.

Another powerful driver of the fertility industry is social conditioning, necessitating us to pass on our race. Class society, where private property is valued, reinforces the desire for progeny as a means of passing on property. Patriarchy bequeaths an inferior position to women and a 'desire' for a male child. The fertility industry is heralding the return of eugenics – decades after many believed it had received a final burial in Nazi Germany – by fanning the demand for blue-eyed, blonde-haired, Ivy League donors. There is an attempt to create a super race of humans that does not have any defects, or at least any perceived defects. This goes hand-in-hand with capitalism and its need for uniformity – everybody must wear the same brands, shop at the same places and so on. There is a demand for a special kind of human being with specific and similar characteristics. Difference is not considered good for the consolidation of capital as it moves around. This is highlighted particularly well in the documentary 'Frozen Angels': *"We see a minimally informed public, less critical media coverage and only a small window of time remaining for informed democratic discussion before it is slammed shut by the ever increasing weight and interest of the biotech industry who would like to have us believe the transition was inevitable"*.

However, there is a need to engage with the many facets of this issue by moving beyond the obvious. The bio-technology industry today is re-drawing the contours of a post-industrial society with the race to secure rights over biological

material. Biotechnology has altered the way human tissues are regarded in law, politics, economics, and society. Earlier, human organs were seen as 'entangled' in the human body since they cannot be stored outside for a substantial length of time. Now the embryo can be 'disentangled': banked, copied, circulated, and, most importantly, protected by intellectual property.

Informed consent is used as a mechanism to formalise and regulate transfer of tissues to researchers and industry, including their IPR (intellectual property rights). When one signs an informed consent form, one is also signing off rights over one's own body tissues. This is important because it determines the transfer of intellectual property to attract venture capital for biotech companies. Even individuals who privately bank their cord-blood are investing in future biotechnologies.

The fertility industry is a cog in the giant wheel of global capital which is moving forward and seeks a potentially inexhaustible renewable commodity – the cell or the tissue. It requires little energy to reproduce. It is not just the source of body parts but of food, medicines, fuel and new materials. This is fuelling today the 'engineering of life' itself, and at the core of the biotech industry lies the vision of the transformation of biological life into a new source for surplus value. This may have been out of the realm of even science fiction fifty years back, but today it falls within the realm of possibility, wherein a new material can be made out of living tissue, protected by IPR and exploitative companies. In a sense, life itself becomes the new commodity of capitalism.

Living tissue is the commodity of the future, promoting the patenting of life itself. We can see the consolidation of large food and chemicals industries with bio-technology.

Biotechnology firms are funded by venture capitalists, especially in the US, based not on what they know it can deliver but on speculations about what it might. Thirty years back this would not have been possible because speculative financial flows were not the drivers of the global capitalist economy, and would not have been funding the biotech industry on the basis of what it promised to deliver in future. But, today speculative financial capital looks for much larger returns than what you get from the brick and mortar economy.

There are some lessons to be learnt from the market control over the food market. For instance, investment funds (through stock market trading) control up to 60 per cent of the wheat traded on the world's biggest commodity markets. Billions of dollars are being poured in as 'hot' money into food commodities even in the midst of the food crisis in order to escape sliding stock markets and the credit crunch. Though it is not apparent from news reporting, we are going through a food crisis; the per capita availability of food in India has never been this low since Independence. Speculative money in commodities futures has ballooned from US \$ 5 billion in 2000 to US \$ 175 billion in 2007. We need to ask ourselves the question: do we see the future of bio-technology and post-industrial society in the likes of Bayer AG, Monsanto and Syngenta?

In conclusion, science and technology are social creations. Not all advances will lead to destruction, but just because we know how to do something does not mean we should do it. Perhaps we need to put part of the bio-technology genie back into the bottle and make the other part a friendly genie. Society has the task of shaping the boundaries within which science and technology will be applied.



## **Biogenetic Futures: Patents and Property, Speculation and Services**

*Sarah Sexton*

It is important to look at some parallels, connections and disjunctures between modern finance and the fertility and biotech industries, from which five themes emerge: the future, speculation, patents, services, and regulation.

The future plays a key role in Assisted Reproductive Technology and biogenetic research. Promises and hopes create an imagined future of a healthy child, even though, four out of five ART attempts on average will not result in a 'take-home baby'. Within human-related biotech research, the imagined future is one in which diseases and conditions can be treated, cured, or do not occur in the first place. It is necessary to mobilise this hoped-for future so as to get public and financial support.

The future also plays a key role in the modern financial world and the current financial crisis. Or rather 'a' future: a legal agreement to buy or sell a specified asset at a specified price on a specified date in the future. The agreement itself can be bought and sold; those who do so are speculating on whether its price will go up or down in the future so as to make a profit. The agreements, the futures, are based not only on the future prices of rice, grain and other commodities but also of interest rates, exchange rates, currency rates and other intangibles.

Futures have been cross-linked and embedded in yet more financial agreements (such as options, swaps and forwards) to such an extent that financial markets, rather than selling futures on tangible things, are more in the business of, as Melinda Cooper puts it, "accumulating promise from promise." But despite seeming complicated

and technical, financial markets essentially operate as bookmakers.

The new financial futures markets and practices did not arise out of supply and demand, but were actively planned, pushed and calculated to engineer demand for something that few initially wanted. This involved constructing a 'public interest' argument to overcome legislation that outlawed them.

Financial futures have enabled the biotech industry through venture capital, particularly in the United States. Biotech companies financed this way are valued not according to what they produce but according to the possibility of future productivity of profit.

To generate value in the present, however, the vision of the future does not in fact, need to be realised or expectations fulfilled. What does this suggest for our critiques of the potential dangers of the futures promised? Should we take these promises at such face value?

For example, for over 10 years, it has been said that human embryonic stem cells offer the best chance of enabling everyone to have a personal repair kit when we get old or sick; laws were changed in many countries to allow the research to go ahead – research that would require thousands of women's eggs. Many of us raised concerns about who they would come from and how. Yet within the past couple of years, stem cells from adult skin cells (Induced Pluripotent Stem cells or IPS cells) are now considered to be more promising. Would the human embryonic stem cell future have collapsed long before it could be realised without any help from us? What have our critiques achieved?

Colonising the future is a means of capturing and depoliticising the present – debates ignore the causes of infertility, ill-health and poverty, for instance, or are silent on the lack of access to health care services. Decision-making is

channelised towards an imagined future, distorting priorities, creating misplaced hopes and distracting us from acting on the knowledge we already have about the prevention of illness and disease.

Futures are closely allied with speculation, while speculative finance often drives and mirrors the speculation inherent in the biotechnology industry. In the financial world, speculators increase prices through their bets on the future, especially in the commodities sector. "It is just like secretly hoarding food during a hunger crisis in order to make profits from increasing prices," said financier and billionaire George Soros. When the prices of food stuffs went up in 2007 by between 100 and 400 per cent, the resulting food riots in many parts of the world in 2008 because of food shortages were not attributed, however, to financial speculation, but to 'too many people too little food', middle class people in China and India eating more meat, or Europeans protesting against genetically-engineered food. If women and their families are poor and hungry, it may seem like a positive step to sell their reproductive powers within the ART and related industries.

Patents lie at the heart of speculative capital, particularly as it is deployed in the biotech industry, and are a key mechanism of financial accumulation as well. Some 20 per cent of the human genome has been patented. In the biotech industry, patents are less about protecting innovation than about attracting speculative investment. The patent itself has become the commodity, more than any product the company might eventually manufacture and sell, and more than the genetic sequence on which the patent is based. With a patent, it is more likely that a biotech company can attract investment. The patent itself has speculative value.

The patent games that pharmaceutical companies have long played cast doubt on claims that patents are needed to protect and fund innovation and research. The industry spends more on marketing its products than researching them; much of the research is funded by public sector funds anyway; any money they do spend on research and development is eligible for tax breaks; and new patents are often granted on old drugs.

Patents and other IPR are also used by all large companies to reduce the amount of tax they have to pay on their profits. The practice of 'transfer pricing' enables companies to shift their profits offshore to subsidiaries in tax havens or secrecy jurisdictions.

Just as patents have become commodities, so too have health care services, making them unavailable or inaccessible to many. In the process, health care has become yet another vehicle for financial speculation. The United Kingdom (UK), for instance, has been privatising its publicly funded health service through the back door by means of outsourcing, contracting out and handing over the buildings to the for-profit sector. Three-quarters of IVF cycles take place within the private rather than the public sector. An estimated 26,000 women from the UK go abroad every year, particularly to countries in Southern and Eastern Europe, for fertility treatment because it is cheaper or because it will be provided despite their age or so as to obtain the donor eggs or sperm that are not available in the UK. (The UK regulator, the Human Fertilisation and Embryology Authority (HFEA)<sup>1</sup>, is now suggesting that British law should be amended to increase the amount of money that can be paid to egg donors in the country so as to limit the exploitation of poorer women overseas).

Women who go to another country to buy IVF and its related 'services' and



'products' are often labeled, perhaps pejoratively, as 'reproductive tourists'. Other descriptions of the practice are 'cross-border reproductive care' and even 'cross-border reproductive labour markets'. These terms remind us of the services agreement of the WTO (World Trade Organisation); GATS (General Agreement on Trade in Services) aims to enable more cross-border trade in services!

GATS has had significant consequences for health and health care services in the 15 or so years in which it has been in effect. It was first instigated in the seventies by two financial services organisations with a couple of goals in mind: to obtain a multilateral agreement on investment that would enable capital to cross borders with few restrictions, and to ward off regulation of new financial innovations such as futures. These two organisations were the credit card company American Express and the American Insurance Group (AIG) which is one of the primary entities at the heart of triggering the 2007-2008 financial collapse through its speculative use of futures.

The financial crisis is often blamed on the lack of regulation, as are many of the unsafe and exploitative practices associated with the ART industry and associated biotech research. In fact, much of the financial innovation of the past few decades was designed explicitly to get around laws and regulations or to profit from different regulations in different countries – something that also happens in the cross-border ART industry and in biotech research.

In the financial world, whatever new regulations are introduced, financiers will seek a way around them and engender new risks (and new profits) in the process. There is also the risk of 'regulatory capture': those being regulated taking charge of or influencing the regulation such that it accommodates rather than regulates them. The same process has occurred within the UK's regulation of the

ART industry over the past two decades; the UK now has, as Franklin and Roberts (2006) note, "the world's most elaborate regulations governing reproductive medicine while also offering one of the most liberal climates for experimental treatments and research".

Given that each new regulation is a new opportunity for accumulation, commentators on the financial crisis have stressed that regulation will do little to undermine the structures of power that support the finance industry unless policy reform is rooted in wider grassroots mobilisation for change and movement building that might contribute to deeper structural change. And that will create the political pressure to ensure that regulations are not weakened by the financial services industry.

## **Coordinators' Comments**

### ***Manisha Gupte***

- There is a need to explore the business interests behind the making of 'healthy' babies. The business of biotechnology is related to the politics of naturalising certain kinds of diseases, by labeling some and not others. Are we looking at trans-nationalising illnesses, with new illnesses (bird flu, swine flu) coming in, without solving the problems that exist in poor nations?
- To be able to grasp how pharmaceutical companies, surgeons and technologies are implicated in the ART industry, the connection between the 'moment of birth industry' and the 'moment of death industry' need to be understood. A critical question here is that of power: who will have the power to own, decide and exercise control or regulation?
- The 'nothingness' of a womb-person is already evident, even as body parts like

sperms and ova have the ability to pass on citizenship and confer power that a whole human cannot.

- The inter-linkages of bio-technology with power, caste, class, heteronormativity, ableism, etc. have to be established, as ARTs cannot be disentangled from the larger bio-technology industry.

### **Judy Norsigian**

- Challenging the culture of greed that is worshipped in many of our communities is a difficult yet important task. Without regulation of the financial markets, collapses are likely again and again. During the recent financial crisis, low income people who took mortgages were blamed rather than those who issued them. Though some in Congress and in Industry want regulation, powerful lobbies like AIG continue to sway inordinate power and control. Further, the people themselves have not raised their voices and voted to make these issues central.
- In the US, the gestational mother is given the status of *one* of the mothers. We must insist that elements like this are preserved, and also that peculiarities in different countries do not leave the offspring without an identity.
- The ideology of choice is being embraced unquestioningly. As feminists, we need to say that sometimes choices have to be constrained in the larger interest.
- Despite laws in the United States that do not allow the patenting of life forms, the US Patent and Trade Office has patented life forms like genes. These patents were granted to preserve the right to get, and to

research, better treatments, when in fact, patenting hinders competition for research for the best treatments and technologies. We can use the same arguments that are used to preserve patents to undermine them. This is what the ACLU (American Civil Liberties Union) is trying to do in an ongoing lawsuit.

- Information is key in the discussion on fertility drugs. This is seriously lacking today. A woman cannot give informed consent without enough information, and enough evidence has not been collected on safety risks.

### **Discussion Points<sup>1</sup>**

- There are not only parallels between the trajectories of finance and bio-technology (making it a business of hope), they are also connected. Biotechnology and finance markets both depend on futures, and are intertwined in that they take something private and make a public offering (stock markets, for instance).
- It is clear that politics and economics intersect in ARTs. In fact, politics plays an enabling role. The vision of the neo-liberal Indian state and the vision of the neo-liberal ART industry are similar. The Indian state is well aware that an entire town in Gujarat has a surrogate in every second home, but has not proactively regulated the phenomenon. While some feminists want regulation of technology, others do not, because regulation is seen as always 'light years behind the technology itself'.
- The problematic status of the citizenship of babies born through surrogacy reveals that governments are ill-equipped to

<sup>1</sup> The 'Discussion Points' capture the comments that were made either by participants from the floor, or by the speakers in response to questions by participants and co-ordinators.



handle the situations arising out of ARTs. In recent times, a surrogacy case that has got a lot of media coverage because of disputed citizenship is that of German twins born to an Indian surrogate mother. It is evident that the woman carrying the foetus for nine months is invisibilised in the surrogacy process.

- There is a need to discuss the ethics of patenting biological material. The industry supports patenting because they want to beat the competition. Even as we examine the colonisation of the future, we need to understand the recolonisation of the past, since genes are from the past. Essentially all intellectual property is the 'inherited property' of humankind. In 2008, a group of aboriginal people in Australia

resisted the government's attempt to get them to lease their land for 99 years for AUS \$ 60 million. The government thought they would get returns from the land in the future, which they wanted to capitalise on. The aboriginal people held out despite the promise of health and other facilities, only to maintain their intellectual property rights in the future.

- ARTs are not just about trade in babies but also about trade in women's bodies, for instance through the hyperstimulation of ovaries and embryos to create more capital. There are similarities and differences between the ART industry and sex work, particularly with respect to health. We need to investigate what is considered 'morally reprehensible' and why.







International Consultation on commercial, economic and ethical aspects of  
Assisted Reproductive Technologies (ARTs)

January 22-24, 2010, New Delhi

Santa - Resource Group for Women and Health



Shaping the Fertility Industry: Challenges and Strategies  
for Movement Building

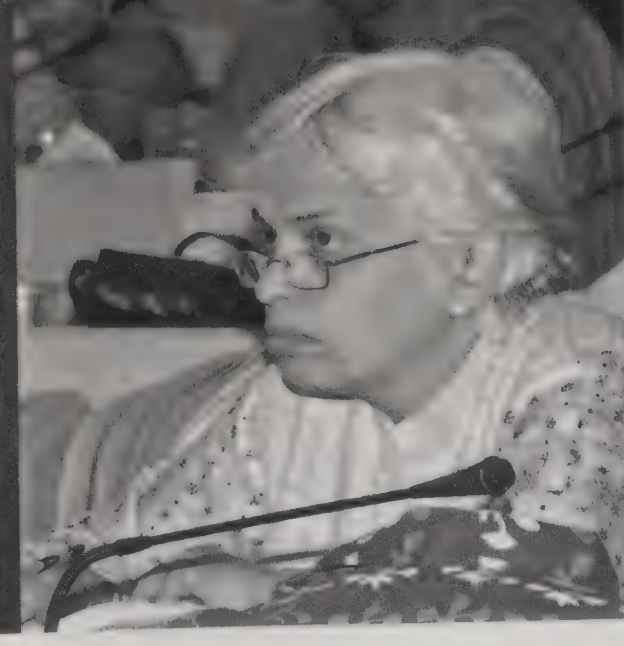
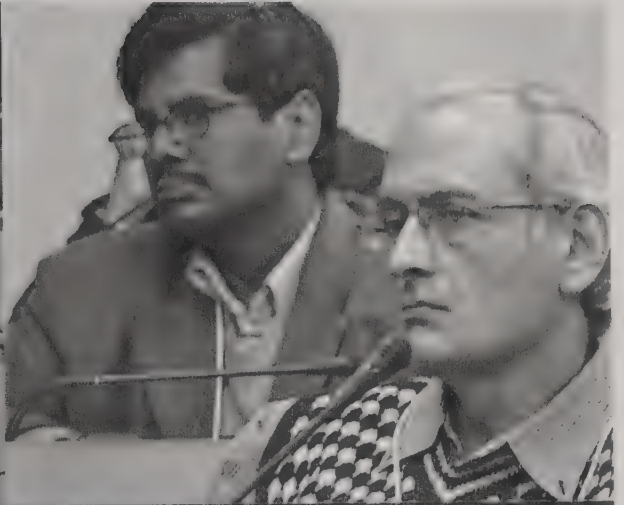
International Consultation on commercial, economic and ethical aspects of  
Assisted Reproductive Technologies (ARTs)

January 22-24, 2010, New Delhi

Santa - Resource Group for Women and Health













# Global Experiences: Asia Pacific

Coordinators: Mohan Rao and Shree Mulay

## **From the Cutting Edge to 'Business as Usual': What does the future hold for women in Australia's mainstreaming of ARTs?**

*Renate Klein*

Twelve of the first fifteen test tube babies after Louise Brown's birth in 1978 were born in Australia, and many of the world's 'firsts' (such as the first donor egg baby and the first ice baby) made regular headlines. Feminist resistance formed quickly, with Robyn Rowland as the most vocal critic. Following up from the foundation of FINRRAGE (Feminist International Network of Resistance to Reproductive and Genetic Engineering), critical community discussion questioned the benevolence of these technologies for women. The laws passed in Victoria in 1984 – the first anywhere in the world – held a lot of restrictions for the ART industry, amongst them a prohibition of all types of surrogacy that amazingly stayed in place until 2008.

In 1987, embryo experimentation for micro-injection experiments was opposed because it necessitated experimentation on women. The eggs for the embryos are extracted from women's bodies after dangerous drugs and egg harvesting procedures. Ironically, now twenty years later, the same words are being used to oppose egg 'donation' for Somatic Cell Nucleus Transfer (SCNT) cloning research. Indeed, Victoria passed legislation

in October 1987 to restrict embryo experimentation to 22 hours rather than the 14 days that IVF scientists wanted. But micro-injection had already been performed in Sydney, where no restricting laws existed. This shows that scientists will always find loopholes, which is why resistance has to start with opposition and not negotiations on regulation.

A 1988 critique (Klein and Rowland) of fertility drugs was ferociously attacked by the IVF industry, but a research from Los Angeles in 1994 (Whittemore and Rossing) vindicated this work. A label mentioning the risk of ovarian cancer was placed on Clomiphene, though its usage has not stopped.

For some time in the eighties and early nineties, international feminist resistance was able to at least slow down the technologies and to bring them into mainstream discussion. FINRRAGE successfully connected the two sides of the coin: 'new' reproductive technologies and 'old' ones such as harmful contraceptives, and drew attention to the violence of population control against women in the so-called Third World versus the pro-natalist fertility industry in the global North and for the elites in the global South.

Now in the 21<sup>st</sup> century, Australia's IVF industry has gone mainstream, consisting of a number of clinics, including chains,

around the country. Little resistance or even community discussion is still alive. The media is unresponsive, and a few journalists occasionally report on the high numbers of premature and multiple births, and the increased post natal depression in women after IVF births. Research published by Australian epidemiologist Carol Bower in 2003 showed that children born through IVF are twice as likely to have birth defects, like Down's Syndrome, Spina Bifida, etc., than other children. American researchers recently reported 'epigenetic differences' in babies born from IVF that account for 'greater risk of diseases such as obesity and diabetes later in life'. It is puzzling that such scary results do not gain traction in the public mind. Women who suffer ill-effects, or their babies do, no longer speak out due to the 'choice trap'. They believe that since it was their 'choice' to use IVF, the problems must be their fault.

The NHMRC (National Health and Medical Research Council) did not follow through on its recommendations in a 1995 report to undertake a study of the health of women who had gone through IVF. It appears that such a study would have been too costly and too difficult. In other words, today no one links the general health of the current cohort of 50+ years old Australian women to their IVF treatments in the eighties, which is serious neglect.

As for the development of surrogacy in Australia, as far as the uncritical mainstream pro-natalist public is concerned, any kind of infertility is a tragedy, and altruistic surrogacy is to be applauded. We are told that infertility is on the rise although there are no new surveys conducted on infertility rates and there is no comprehensive data.

The practice of surrogacy was controversial in the eighties. In 1988, there was the famous

Kirkman case in the state of Victoria with a surrogacy arrangement between two sisters producing baby Alice, in which power differences between the two women were extraordinarily stark. It was then that 'gestational surrogacy' was first spoken of, and it was said by doctors that if the so-called surrogate mother didn't use her own eggs, she was not the baby's 'genetic' mother and no attachment could ensue. At the time, public opinion was mostly against the Kirkman sisters and in 1988 laws were enacted in Victoria that made all forms of surrogacy a punishable offence.

This state of affairs began to change in 2006 when a federal politician was involved in a high-profile surrogacy arrangement. He and his wife had to travel back and forth to Sydney in New South Wales, which does not have any laws on surrogacy (or ARTs). Talk-back radio revealed the change in public sentiment that had occurred: overwhelmingly the Conroys were pitied and restricting laws condemned. It was quite disturbing that some women who had acted as so-called surrogate mothers in other states, called themselves 'just an oven' in one case, 'a suitcase' in another.

National Guidelines on Surrogacy are yet to be developed but in Victoria as of 1 January 2010 the Assisted Reproductive Technology Bill 2008 is being enacted. Its most distressing part, from a women-centered perspective, is that it will make the birth mother invisible. It allows for application to the court for 'substitute parentage orders', which will transfer legal parentage from the surrogate mother and her partner (if any) to the commissioning parents. A new birth certificate will be issued to the commissioning parents once the substitute parentage order has been made. The state will officially sanction the reduction of a real live woman to her womb, and will even deny her the right to the 'products' of this womb.



This is reproductive slavery by another name, and signifies the ultimate legal elimination of women.

In terms of bio-technology, and in particular the international hype around embryonic stem cells, Australia today is not the 'world leader' it would have liked to be. This, despite the government's endorsement and generous funding of the Australian Stem Cell Centre. Also, in 2002, Federal parliament cleared the way for stem cell research using left-over embryos from IVF while prohibiting the Dolly method: the production of SCNT embryos which necessitate unfertilised eggs. But, four years later in 2006, this Act was amended and SCNT cloning is now allowed.

Visible feminist resistance sprang into action as FINRRAGE and CATWA (Coalition Against Trafficking in Women, Australia) joined hands with the international group *Hands Off Our Ovaries* to point out the dangers for women, of 'donating' eggs. Although the campaign – using the term 'eggsploitation' – garnered some media sympathy, the common public view supporting embryonic stem cell research – as progressive science that reduces suffering – remained unchanged. The central and dangerous role of women as egg donors remained invisible. Nevertheless, the feminist campaign almost succeeded; the Federal Cloning Amendment Bill 2006 won with only one vote in the Senate.

Despite the Australian Stem Cell Centre's particularly bad year in 2007, unfortunately in 2010, the Amendment Act 2006 will come up for review and this year's battleground will centre around the quest for payment of egg 'donors'.

Weary of any new miracle technologies, the upcoming feminist campaign will continue to focus on the health risks for women. It

will be pointed out that as of 31 March 2009, only three out of 10 current embryo research licences handed out since 2002, use SCNT research. Although a staggering number of eggs were granted, no embryonic stem cell lines have been created. The source of the eggs was not specified, other than saying they were 'clinically unusable'. If and when eggs from women will be used, it remains to be seen if any mention is made in the Licencing Committee's report on their state of health during and after the said egg provision.

In Australia, feminist resistance waned in the second half of the nineties and the women's health movement was crumbling as well. In 1996, the Women's Health Policy was axed because it was perceived as discriminating against men. News stories are increasingly endorsing the pharmaceutical sales pitch that miracle technologies will save us from all ills. Measuring, testing, ticking boxes is fast becoming the proper way of health assessment, unfortunately, very much endorsed by the current technology-friendly Labour government. 'Personalised medicine' is the catch-cry for the rich of the world and 'choice' the magic word, except the choice to say 'no' to technologies and treatments that violate bodily integrity and turn most of us into walking diseases and 'chemical citizens'. It is no wonder that within such a framework, reproductive technologies are simply seen as good tools in the 'war chest' of the health technologists.

But, what about the remaining women's health movement? Sadly, managerialism now dominates what is left of its public presence. Caution must be observed to avoid the trivialisation of feminist concerns. For instance, in the feminist campaign against SCNT cloning in 2006, reproductive choice advocate Lesley Cannold famously claimed that 'donating' eggs was no different than a blood transfusion.

Young people concerned with ecology in the context of climate change, must be made to recognise the similarities between treating the bodies of women as experimental objects and the violence against land and indigenous peoples. As we hope for a new politicisation (and re-politicisation), we must also note the need to reassess current liberal regulation policies, given that since scientists go as far as they can, regulation just presents an opportunity to find loopholes. There should be a moratorium on these technologies and studies should be conducted to investigate the health of women who have been harmed by reproductive technologies and genetic engineering.

### **Assisted Reproductive Technologies at the Crossroads: Neoliberal Economy, National Depopulation Crisis and the Politics of Reproduction in South Korea**

*Young-Gyung Paik*

While the regulation of ova extraction and IVF had been a feminist concern even before the Hwang Woo Suk scandal, the case provided an impetus for the regulation of ARTs in South Korea. The discourse of the national depopulation crisis has framed the policy concerns and public debates on bioethical issues in contemporary South Korea. Solving the reproductive and economic crisis of the country through stem cell research and IVF has taken priority over ethical considerations.

In recent years, the extremely low fertility rate (1.19 children per woman in 2007) and the rapid ageing of the population has been a source of concern for the Korean state and society. There is a conflict of interest between the state's need to encourage stem cell research and IVF to 'save the nation', and the introduction of ethical regulations and global standards at the same time. Yet, it is clear from the UK case that well-established regulation

can exist to *enable* the bio-technological research industry.

In Korea, the bioethical regulations that are considered necessary to facilitate research and industry exist now, but it is difficult to say if ARTs are being better regulated than at the time of the Hwang scandal. Moreover, by forbidding ova donation exclusively for research and making researchers use only 'remaining' ova, the close connection between fertility clinics and human embryonic stem cell research has been reinforced. A new Act forbidding the commercial trade of gametes became effective in 2008. The cases of internet-based ova trafficking and surrogacy were reported and some traders were arrested by the police. Unlike the previous instance where agencies were involved at least in the area of ova donation, which now mostly takes the form of voluntary transaction between two private parties pretending to be relatives or close friends, and cannot be detected and prosecuted easily. While the Act allows the compensation of actual expenses only, even the official amount of compensation can be up to US \$ 1200, which is enough money to lure young women in need, especially in a financial crisis. The actual price of ova donation is known to be around two or three times more.

In 2009, after a long debate, the National Bioethics Committee granted permission for human embryonic stem cell research to a bio-company affiliated to one of the most famous fertility clinics. In this sense, despite the changes after the Hwang scandal, many problematic situations continue. While human embryonic stem cell research had been suspended for three years, following the revision of the Bioethics and Safety Act, the field of somatic stem cell began to flourish as an ethics-free alternative to conduct stem cell research. Cosmetic products containing stem cells are becoming popular with



consumers. Soft tissue augmentation using fat derived stem cells has been applied to a range of augmentations like breast, penis, rhinoplasty, etc. In fact, the drive behind the stem cell therapy boom at local clinics was to find services that were not covered by national health insurance. Especially since the IMF (International Monetary Fund) economic crisis in the late nineties, local clinics providing primary health care have been the victims of neo-liberalisation. At the same time, soft tissue augmentation with ESC (Embryonic Stem Cell) injection has accelerated the commercialisation of the health care system, and has been extracting local clinicians from non-lucrative but essential medical services.

In a major shift since the Hwang scandal, these issues have begun to be understood as bioethical or technical issues rather than activist concerns; the institutionalisation and professionalisation of bioethics has taken place; the authority of experts has been emphasised in the area of bioethics; and the role of women's rights activists has been even more marginalised. While this trend itself is problematic, this institutionalised bioethics has shown a particular incapacity to deal with pro-natalist policy, or the ever-growing force of market.

The first legal attempt in Korea to incorporate bioethical issues was the enacting of the Genetic Engineering Promotion Law (now known as the Biotechnology Promotion Law), submitted by members of the National Assembly in 1983. Encouraged by foreign successes, groups of Korean scientists joined in on research for human embryonic cloning. A series of attempts to produce human embryonic stem cells in the early 2000s sparked debate among religious and civic groups, some of which started to advocate the need for the bioethical regulation on the issue of stem cell research

in South Korea. In response, the Bioethics and Safety Act was enacted in 2004 (and came into effect in 2005) 'to secure safety and ethics of bio-technology' in the country. However, the Act was criticised by sections of the citizenry, including academics, legal professionals and religious leaders, for not pursuing safety and ethics aggressively, but functioning instead to promote biotechnology. The contentious issue at this point was not about ova, but whether to allow embryo cloning. Feminist groups pointed out that because there were no official regulations on IVF procedures in South Korea, there were no means to regulate the sale of eggs, surrogacy or the creation of embryos at fertility clinics. The warning was to prove prophetic.

In 2005, the Hwang Woo Suk scandal and the arrest of international ova traffickers exposed infertility clinics as the loci of commodified ova supply both for research and for infertility treatment in South Korea. In early November 2005, the Korean National Police Cyber Crime Investigation arrested a company called DNA bank and several other egg brokers, accusing them of ova trafficking through the internet. Soon after, there was a report that Hwang's team used trafficked ova for their stem cell research. A public debate on the bioethical issues in Assisted Reproduction followed, and the Ministry of Health and Welfare, the ruling party, the opposition party and a feminist NGO each prepared a different bill of bioethics law (4 in total) to regulate the legitimate use of ARTs.

In April 2007, the Ministry of Health and Welfare synthesised the different Bills and finalised two closely connected Bills to be presented to the National Assembly: one was a revision of the Bioethics and Safety Act and the other served to introduce the Protection and Regulation of Germ Cells Act.

The reformed Bioethics Law was passed in the National Assembly in April 2007, and became effective in May 2008. Some of the provisions of the law are:

- Ova donation was allowed for infertility treatment, but prohibited for the exclusive purpose of scientific research.
- Only 'remaining eggs', obtained for infertility treatment but unused, or those that failed to fertilise, could be used for stem cell research with the informed consent of donors.

Interest groups had reservations about the new bills. Many religious groups, especially Catholics and Protestants, expressed their dissatisfaction that the new Bills would still allow research on human cloning. The gravest problem was the concept of 'remaining eggs'. Bio-technologists, scientists and medical doctors argued that the concept of 'remaining eggs' was ridiculous. What they needed for stem cell research was not poor quality leftover eggs but fresh and mature eggs. They argued that the new eggs would make stem cell research impossible in South Korea. The new Bills were, in fact, self contradictory. While allowing or even trying to promote stem cell research, it denied a legitimate way to obtain a substantial number of eggs that can be used for research. They were seen as the result of a compromise between the ethical problems and the fear of losing initiative in international competition in the bio-technological research industry, compounded by fears of depopulation. Producing one's own offspring came to take priority over the ethical concerns about the commodification of eggs, surrogacy or the indiscriminate use of IVF technologies.

In the policy of subsidising IVF for South Korean couples, what is at stake is not only how to increase the fertility rate, but also how to produce proper South Korean citizenry

in order to secure the future of the nation. In the debate over the current population crisis, a more lenient immigration policy is regarded as inevitable, while at the same time, deemed a source of crisis destroying ethnic homogeneity. Therefore, the issue is not simply how to increase the overall population of South Koreans, but how to encourage childbirth among the 'right' sector of normative middle class married South Koreans.

Therefore, in 2006, even after the back-scratching alliance of fertility clinics and stem cell research was revealed, the state simply decided to promote and subsidise IVF procedures for infertile couples without introducing comprehensive regulation of fertility clinics. At the same time, measures to enhance reproductive health in general have been ignored. An anti-abortion campaign is being supported by the state and regulation of abortion is being tightened. Yet, the distribution of contraceptives or education in sexual and reproductive health for young adults is under-funded and does not get policy attention.

The state was criticised by experts for encouraging unnecessarily invasive procedures and was suspected of having interests in promoting bio-technology and the fertility industry. In fact, the Ministry of Health and Welfare once called plastic surgery, health screening and the IVF industry the three 'most promising' fields for medical tourism in South Korea. It was also evident that the state was less interested in introducing the regulation of IVF for women's health than it was in promoting the South Korean IVF industry and bio-technology, both highly dependent on human ova supplies.

In this context, surrogacy and assisted reproduction are also framed in the context



of national anxieties over low fertility rates and economic insecurity. Low fertility has framed the debates primarily as 'plight of the infertile' in South Korea. This has been double-edged for childless couples, as they have been subject to rhetoric that casts them as the source of the national crisis, and are excluded from tax reforms and housing programmes that favour families with children. Many couples are relieved that infertility has moved from being a private misfortune to a state-recognised social problem, and they can now take advantage of public funding. Yet, on the other side, many now encounter greater pressure to undergo IVF. The language of the safe population policy defines infertility as a disease requiring immediate medical intervention, forcing childless couples to obtain treatment. Celebrity doctors have told the media that there is no 'absolute infertility'.

Childless couples often imagine that IVF procedures can help them get pregnant quickly and patients of infertility clinics encourage others to skip artificial insemination and to start IVF treatment as soon as possible, in order to save time, because the success rates of IVF are higher. After repeated IVF attempts, many couples find their initial optimism misplaced and are left physically and financially exhausted, a state described as 'torture by hope'. At such a time, some begin considering surrogacy seriously. Presented as the last means to have children, surrogacy can be neither fully legalised nor prohibited by the South Korean state. Therefore, while debates focus on how only altruistic surrogacy can be fully allowed and not commercial surrogacy, the reformed Acts provide only minimal legal regulation of surrogacy. Public bioethical debates often focus on regulation and institutional practice, while ethics is understood as a person's personal moral judgement.

The South Korean situation underscores the importance of the wider context in which meanings of ARTs emerge. The proposed Bills had to find their ethical guarantee in a normalised concept of family. Consequently, while the Bills were drafted to address ethical problems in stem cell research and assisted reproduction, the ethics of the state depopulation policy, the ethics of the normative concept of Korean family and Korean nation, or the ethics of the public health care system, were seldom questioned. Despite official perceptions of surrogacy as unethical, anxiety over the national fertility crisis has framed surrogacy as the last means for the infertile to have children and consequently provide the much-needed future labour force of the country.

The discourse of the national crisis has framed and conditioned the way the public imagines the kind of suffering that deserves public recognition, the kind of people who have the right to reproduce by using ARTs and eventually the right and duty of the citizen in contemporary South Korea. Feminists in South Korea have been facing difficulties in their effort to regulate ARTs. In this rapidly globalising world, however, a situation in one country also generates a context for other countries, making possible timely and necessary feminist intervention beyond borders.

## **Coordinators' Comments**

### ***Shree Mulay***

The tendency to conflate infertility rate with birth rate must be avoided. There is a general belief that the infertility rates have increased. We have to examine if this is being confused with people opting to not have children due to the high costs of bringing them up, or with the fact that reproductive spans have reduced due to children being born at a later age than

earlier generations. If the latter is the case, then increasing 'infertility' rates may actually be a natural course of fertility declining with age.

### **Mohan Rao**

It is ironic that altruism and maternal love (in surrogacy) is being reified in a neoliberal world that asserts competitiveness in every other sphere of life. The difference between commercial and altruistic surrogacy needs to be identified.

### **Discussion Points**

- In 1984 there was a law prohibiting ARTs, including surrogacy, in the state of Victoria (Australia) but it took until 1988 for it to be enacted. At the time, there was a strong public debate around the issue, particularly with the famous Kirkman sisters' case. Now, especially for the last ten years, the debate has died down altogether. People simply don't know how low the success rates are and how dangerous the drugs used in infertility 'treatments' are. The notion of the 'good, altruistic' woman is so strong that women surrogates call themselves 'just a suitcase'. It is not clear how this transition and alienation from our bodies has come about. Perhaps the notion that technology can solve anything is all too prevalent now.
- Australia is a pro-natalist country that wants its people to have more babies. The fertility rate has been rising slightly. In fact, two years back the former treasurer said that Australian women should have three children - one for the mother, one for the father and one for the country! However, it is very difficult to adopt in Australia, and inter-country adoption has received some bad press. In fact, relinquishing mothers have come forward to speak about the heartache that adoption has caused them.
- A liability case has been booked against a clinic in Canberra, Australia where a lesbian couple had two children because two embryos were implanted instead of one, despite their objection. The case is still underway, and the couple has appealed on grounds of inability to bear the costs of bringing up two children.
- It is not that the IVF industry is flourishing in South Korea because of a declining fertility rate. The IVF business was flourishing even before the fertility rates dropped, and was the basis of the bio-technology business. The difference is that now IVF in Korea is subsidised by the state, and is also funded by private corporations. There are so many IVF doctors in Korea that they were not able to make much money, and so they lobbied for the state to do something about the declining fertility rate. But there really aren't many interventions the state can initiate to raise the fertility rate. Unlike family planning, people cannot be forced to have more babies.
- Korea has always been upheld as a country where regulation of industry has worked. It has regulated ultrasounds and sex selection. However, it is evident that a state which is capable of regulation and implementation does not seem to be doing what it could to regulate bio-technology. This is because the state has vested interests in not regulating bio-technology too much. Further, the experience with sex selective abortions is evidence that people find ways to evade regulations when they are in place. Statistics from as recent as the late 1990s and early



2000s show that there was a sex ratio problem in Korea. But more recently, cultural attitudes and people's expectations are changing. Now the sex ratio is within the normal range, with more girls than boys.

- Regarding the kinship concept in South Korea, the proposed bill encourages donation between siblings, because the idea is that if gamete donation is happening among kin, then there will be no 'problem'. It has even been suggested that a father-in-law is the ideal sperm donor for his grandchild because the family genes will be passed on through different generations, without any confusion about the child's identity and lineage. Like surrogacy, this is not considered incest because there is no sex involved. In addition to commercial and altruistic surrogacy, there is also now the concept of a 'natural' surrogacy, wherein subsequent to a failed IVF surrogacy, the surrogate sleeps with the man to conceive.
- In South Korea, adoption is emerging as an option but there aren't so many babies to begin with. Korea has a reputation for

exporting orphans to other countries. This has to do with international adoption agencies that were established during the Korean War. Now more people want to adopt within the country, but some issues remain, like disability. When children have serious disabilities, they can go abroad but it is unlikely that they will be adopted within the country.

- There is no scientific basis for the requisite time gap between subsequent ova retrievals and an upper limit on the number retrieved, which is a different figure in different countries. After heated debate, it was decided that for the South Korean bill, the number of times women can donate eggs will be increased from two to three. This was a compromise figure because scientist groups lobbied saying that while it is very hard to find donors, it is easier to persuade people who have already donated before to donate again.
- More studies are needed to understand the effect of the use of genetically modified foods, pesticides, etc. on declining fertility rates and sperm count.

# Global Experiences: South Asia

Coordinators: Imrana Qadeer and Farida Akhter

## **Medecins Sans Frontiers. This day and This way!**

*Nighat Khan*

A cross-country comparison for South Asia highlights the uncomfortable regional realities of the developing world and of Pakistan in particular. Further, the situation on the ground in Pakistan is probably far more dismal than is represented by statistics from the Federal Bureau of Pakistan.

Some of the key demographic indicators from the WHO's (World Health Organisation) country profile for Pakistan point to an estimated population of anywhere between 160 and 200 million, of which 20 per cent live below the poverty line of US \$ 1.25 a day. Pakistan is the sixth most populous country in the world, ahead of Russia, with a life expectancy for men of 62 years and for women of 63 years. The mortality rate below five years is 97 for every 1,000 live births. No accurate data is available related to the country's fertility rate.

The WHO health profile indicates a high population growth rate in Pakistan, which compounds the high infant and child mortality rates, high maternal mortality ratio and the dual burden of communicable and non-communicable diseases. The high infant and child mortality rates are attributed to malnutrition, diarrhoea, acute respiratory

illnesses, communicable diseases and vaccine preventable diseases; and the high maternal mortality rates are attributed to high fertility rates, low skilled birth attendance rate, illiteracy, malnutrition, and insufficient access to emergency obstetric services.

In terms of human resource indicators, there are 7.4 doctors, 0.4 dentists, 3.4 nurses and midwives, 6.5 hospital beds and 0.9 primary health units for every 10,000 people. While the actual percentage of GDP spent on health is two per cent, an unconvincing 4 per cent is projected by the Federal Bureau of Statistics. A third of the population has no access to potable water. Only 35 per cent women have access to trained personnel during pregnancy and only 33 per cent of them have a trained birth attendant by their side during labour. Clearly, South Asia still has a long way to go to meet the United Nations MDGs (Millennium Development Goals) for maternal and child mortality. This was highlighted by a British Medical Journal paper (ZA Bhutta et al 2004) that compares death rates and other infant, neonatal, perinatal mortality rates of countries in the South Asian region. The 'ironies of fortune' or the disproportionate distribution of wealth is another jarring characteristic of this region.

The existing scenario in the infertility industry in Pakistan is difficult to change. ARTs in Pakistan comprise a range of highly specialised and expensive treatments. There



are 10 IVF clinics in the country, all of which are privately owned. The average cost of one cycle of assisted reproduction is Rs 200,000 (84 Pakistani Rupees equals US \$1). The services on offer are IUI (Intra Uterine Insemination), IVF (In Vitro Fertilisation), ICSI (Intra Cytoplasmic Sperm Injection), PGD (Preimplantation Genetic Diagnosis) and even sex selection. A leading fertility doctor from Lahore recently claimed in an interview that he aimed to 'pioneer' sex selection in the country. In such circumstances, the core concerns are not about the availability of IVF facilities, but rather, about the distribution of wealth and disparity in health economics, regulation and licensing, the franchising of IVF clinics, 'patient hunting' by western clinics, and surrogacy.

Pakistan ranks fairly high in Transparency International's list of the most corrupt nations in the world. With increasing accumulation of wealth by fewer segments of society, a gradual disappearance of the middle class is being witnessed today. The loss of the middle class means that a vast majority in Pakistan is struggling to make ends meet, let alone afford a US \$ 20,000 IVF cycle for a baby. Ironically, it is cheaper for a man to get a new wife than it is to get IVF treatment! This picture of disparity raises the important question about whom the IVF clinics are catering to in Pakistan. The disparity in spending is all too evident – Rs 320 million were spent on building a water fountain at a seaside resort, even as many people have no roofs over their heads and sleep on the streets of Karachi. From transport to food, the gap in income is glaring. In a country where the per capita public health expenditure is a measly Rs 360, the government spent Rs 65 million on the overseas treatment of just 18 high profile 'V.I.Ps' (Very Important Persons), mostly for diseases that could be treated within the country, at a fraction of the cost. Pakistan's

poor kidney 'donors' cater to wealthy clients in the countries of the Middle East. There are a large number of ghost schools which employ and pay salaries to teachers but have no infrastructure and no students.

Further, the state of ART regulation and licensing in the country is alarming. While no centre can open or operate in the West without strict checks and balances by regulatory authorities like the HFEA, anybody with the requisite finances can set up an IVF centre in Pakistan. There is no formal inspection or accreditation of the centres or their claims. Since IVF is a lucrative business abroad, anyone who visits foreign locations like London or Canberra can get hold of someone running a fertility clinic, and start this service in their home city. The health worker (like gynaecologist or bio-technologist) is then trained by the parent clinic in the West for a week or so. Personnel from the parent clinic come over for the setting up of the clinic, and leave soon after. The owner of one such privately owned centre claims, for instance, that his success rate is 70 per cent.

The provision of ARTs in keeping with ethical standards is left to the 'good will' of clinic owners and physicians, which is highly questionable. Lord Winston, one of the UK's early gynaecologists, has critiqued IVF clinics in the West, questioning their non-engagement with the public, non-accountability and profiteering.

The phenomenon of franchising has become rampant in setting up IVF centres in Pakistan. Private IVF centres in the West, particularly Australian centers and even Kings College London, have been instrumental in setting up fertility clinics in Pakistan in exchange for hefty remunerations. The expenses for

setting up the clinics, in turn, are covered by pharmaceutical companies, most of whom are big players in reproductive endocrinology medicines, thereby starting off a vicious cycle. In this franchising, the prices of IVF cycles too are determined by the parent clinics. Therefore, patient hunting and franchising is carried out in countries that are already resource poor.

One such example is that of Concept Fertility Centre, Australia, that has affiliated centers in Canberra, Karachi, Lahore, Kuala Lumpur; and is currently negotiating to establish more such centers in South East Asian countries, and in India. An advertisement from this centre's website urgently seeks both egg and sperm donors, and claims to be 'assisting those couples who have difficulty conceiving' given the 'current fertility rate of 15 per cent.'

Surrogacy is considered illegitimate and immoral by the Sunnis, who form a majority in the largely Muslim country of Pakistan. It is equated to any third party reproduction, which is considered equivalent to infidelity. However, the Shia sect in Iran has found a way around this, and in fact encourages third party reproduction. An analogy can be drawn between surrogacy and organ donation. The poor continue to be exploited, similar to what we have seen in kidney transplant tourism. Therefore, simply because a practice is not encouraged in Islam does not mean it will not happen. Rising surrogacy is a probable future scenario in a country, where there are already instances of young medical students donating sperms in exchange for a pass mark in their exams.

There has been some activity by Western authorities on this front. The task force of the European Society of Human Reproduction and Embryology (ESHRE) makes the case for 'choice' to be provided to infertile couples, by making available affordable treatment in

resource poor settings. This 'choice' needs to be questioned, especially since it is not expected of pharmaceutical companies to provide cheaper drugs in resource poor countries. 'Minimal investigations' are difficult and what is meant by 'low cost interventions' is unclear.

When franchises are set up in regions like South Asia and consultants from the West are brought in by the pharmaceutical industry, the role of the pharmaceutical industry is very murky. This industry encourages western specialists to venture out into the developing world, and also provides financial incentives to trained personnel in developing countries. Specialists are routinely approached to set up fertility centres, with a large amount of cash upfront and embryology training on offer. This is the norm for western companies to kick-start their businesses in the developing world.

In terms of possible solutions and steps for the future, one way forward could be to provide training and education in medical ethics through departments in universities. The attendees for such courses tend to be from diverse backgrounds, including journalists and social scientists in addition to medical practitioners. In conclusion, it becomes important to speak of individual rights versus responsible practices when dealing with this complex and multidimensional issue.

### **Assisted Reproductive Technologies in Nepal: A Brief Picture**

*Pinky Singh Rana*

Nepal is one of the least developed countries in the world. It has to deal with a lot of insurgency and is in a post-conflict state. The women's movement is strong especially compared to the rest of South Asia; however, ART is a new issue and has not been addressed much till now. There is little information and



awareness on these technologies in the public domain.

Prior to the initiation of ARTs in Nepal, India was *the* destination for infertile couples, and continues to be so. For those unable to bear the financial burden of ARTs, faith healers, fervent hopes and prayers are the only other options. Women who are unable to bear children are stigmatised as 'barren' and face social discrimination, as well as mental and physical violence from their spouses and family members. Despite scientific proof, patriarchal norms exonerate the male from any blame. Polygamy is seen as an option for couples facing infertility.

The first known test tube baby in Nepal was born in Kathmandu at Om Hospital in February 2004. Today, the hospital claims a 'success rate' of 40 per cent for IVF and 20 per cent for ICSI. Om Hospital also runs a sperm bank. Currently, a number of clinics are known to be treating infertility in the capital and so far, 200 test tube babies are said to have been delivered. They offer a range of ART services, the most common being IVF and ICSI. Om Hospital claims it is using the best medicines in the world and is following international guidelines. Unlike India, Nepal is not seen as a destination for medical tourism. However, Om hospital claims that people are coming from other parts of the world for treatment.

There is no initiative from the government to regulate ARTs at the policy level. The NGO (Non-Governmental Organisation) sector has given priority to issues like maternal mortality, violence against women and contraception. Consequently, these hospitals and IVF centres are working as per their own rules and regulations.

At the individual level, many women face life-long discrimination since ART services are too costly for them. For others, their

vulnerability is taken advantage of and they go to any length without fully comprehending the repercussions on their bodies. There is lack of information on available services and due to lack of government monitoring, there is no guarantee that quality services are being provided.

**Trials of a single mother:** An economically well-off, single woman, based in Kathmandu got ART treatment in India. She admits that her social acceptance despite this 'aberration' might be because of her economic independence. The hospital, however, required her to provide a father's name for the child which was 'cooked up'. After much pursuit she has been able to obtain a birth certificate and other documents for the child.

In conclusion, there is an urgent need for research to understand the current status of ARTs within Nepal – the number of institutes addressing it, guidelines being followed, profile of recipients, information provided, etc. Research findings must be used to build the capacities of stakeholders involved. There is also a need to learn from experiences of other countries, particularly other South Asian countries.

Strong advocacy is necessary to ensure that ART related guidelines are developed and followed by those providing services. Further, commercialisation and gender-based exploitations must be delved into and necessary policies developed by the government to prevent them.

## **Coordinators' Comments**

### ***Imrana Qadeer***

- The issues that emerged from the presentations can be summarised as: financial attraction; the existence of the mythical baby which becomes a gateway

into medical technology; the production of false knowledge by the industry; and the position of competitive advantage of South Asia and India in particular.

- India's proposed ART bill is the 'best' legislation to promote business – how much money we can make from ARTs seems to be its core concern.

### **Farida Akhter**

- Some of the issues raised brought into focus discussions in South Asia that have hitherto centered on population control and contraceptives. In the last 20 years, donor agencies have focused on 'choice' in reproductive health as a women's issue, but they have not questioned this 'choice'.
- Since ARTs are new technologies, there is lack of information about them, even amongst women's organisations. Issues of religion and economics need to be addressed in ARTs. No religious leader seems to be talking about ARTs although they are being practiced rampantly.
- In Dhaka, only middle class women openly talk about having adopted. Adoptive parents are given the status of legal guardians, and at the time of the child's marriage, the biological father's name is required.

### **Discussion Points**

- A lot of women go from Nepal to India (Calcutta) for IVF treatment, and though more Nepali women have been accessing ARTs within Nepal in recent years, the confidence in treatments across the border is higher. Maybe because of easy accessibility and the apparently higher success rates in India, the tendency is to

go to India for treatment. However, the doctors in Om clinic are Nepali doctors.

- The priority and focus for Nepali feminists have been issues like malnutrition and maternal mortality, which have reduced to a large extent. Although otherwise and overall the Nepali women's movement is extremely active, it has yet to engage with the complexities within the new phenomenon of ARTs. With the current political situation in Nepal, the focus is on constitution building and post-conflict insurgency. Further, in all South Asian countries, the NGO sector is dependent on INGOs (International Non Government Organisation) that have their own agendas, on which ARTs do not really figure as a priority.
- Legal guardianship of the child in countries like Bangladesh is very similar to adoption. Adoption is legal in Pakistan, a country with a high fertility rate where many children are in need of homes. A popular shelter home run by the Edhi Foundation has the longest waiting list for adoption. In fact, a famous pop star in Karachi is a single, unmarried woman who has recently adopted. Islamic law states that adopted children cannot inherit automatically, but one can gift one's inheritance to adopted children.
- The clientele of IVF clinics in Pakistan comprises mainly of the middle and upper middle class. Even if the Pakistani diaspora is accessing ARTs in Pakistan, the numbers are not as huge as in the case of India. If people want to have a child and can afford IVF treatment, they will overlook what religion says. In Pakistan, people are known to have sought treatment even from the more conservative western parts of the

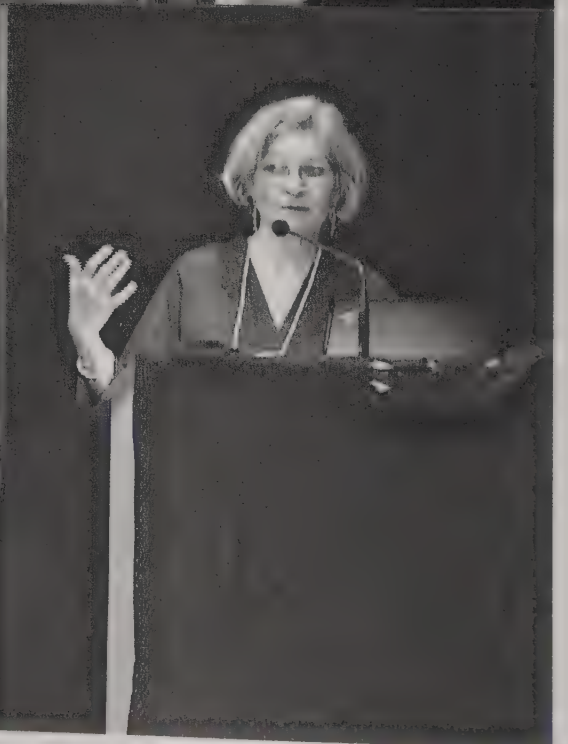


country. Some families have sold their houses and land in pursuit of a male heir of their own genetic origin. On the other hand, there is a different kind of stigma that the upper middle classes in the US face if they can afford IVF but choose not to access it.

- Although abortion is illegal in Pakistan, except on medical grounds, affluent people access abortion in private hospitals. For the rest of the population, abortion is carried out under conditions that put the health and life of women in jeopardy.
- A large number of people in Pakistan have been misguided by fertility management

clinics. Most of them only need stress-counseling, or better management of preventable diseases rather than IVF. Even in cases where it is clear that there will be poor outcome, fertility treatment is carried out to make money. For instance, women with endometriosis of advanced nature are put through IVF drugs and repeated cycles, although medical treatment cannot yield results. Often what is misunderstood as infertility is simply a case of lack of awareness regarding the natural fertility cycle.

- Organ trade in Pakistan is a mix of local and international demand.





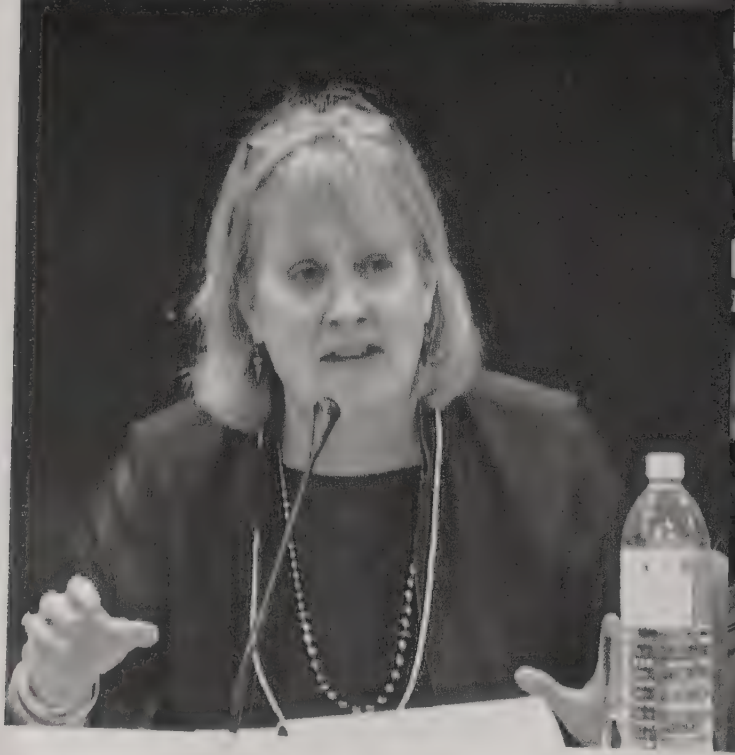
# Unraveling the Fertility Industry: Challenges and Strategies for Movement Building

International Consultation on commercial, economic and ethical aspects of  
Assisted Reproductive Technologies (ARTs)

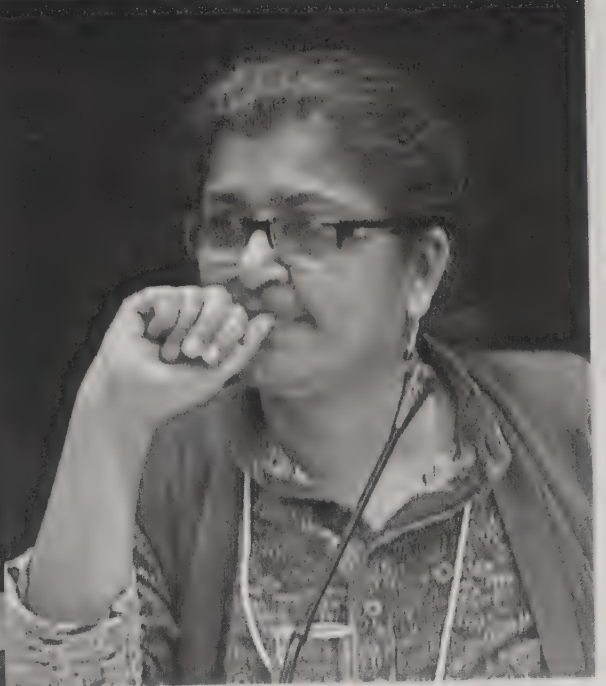
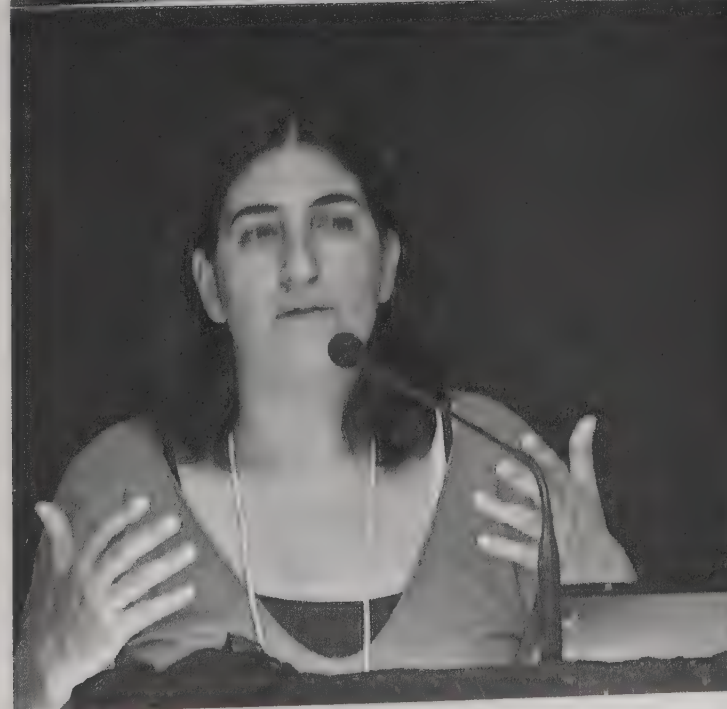
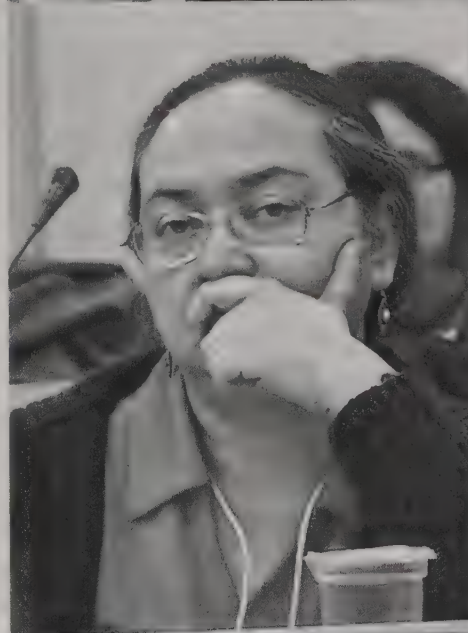
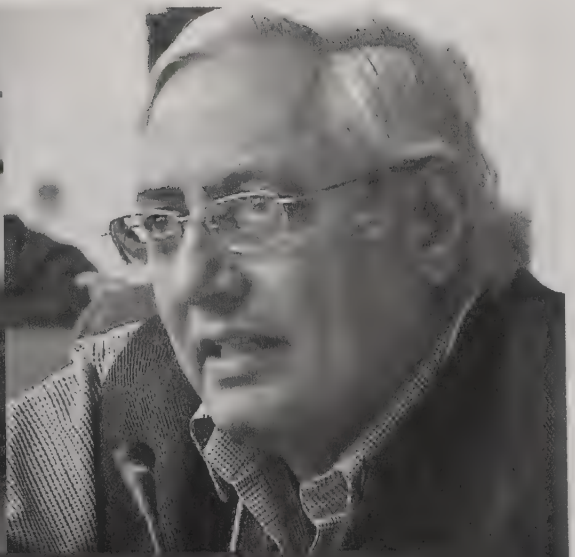
January 22-24, 2010, New Delhi

Samra - Resource Group for Women and Health



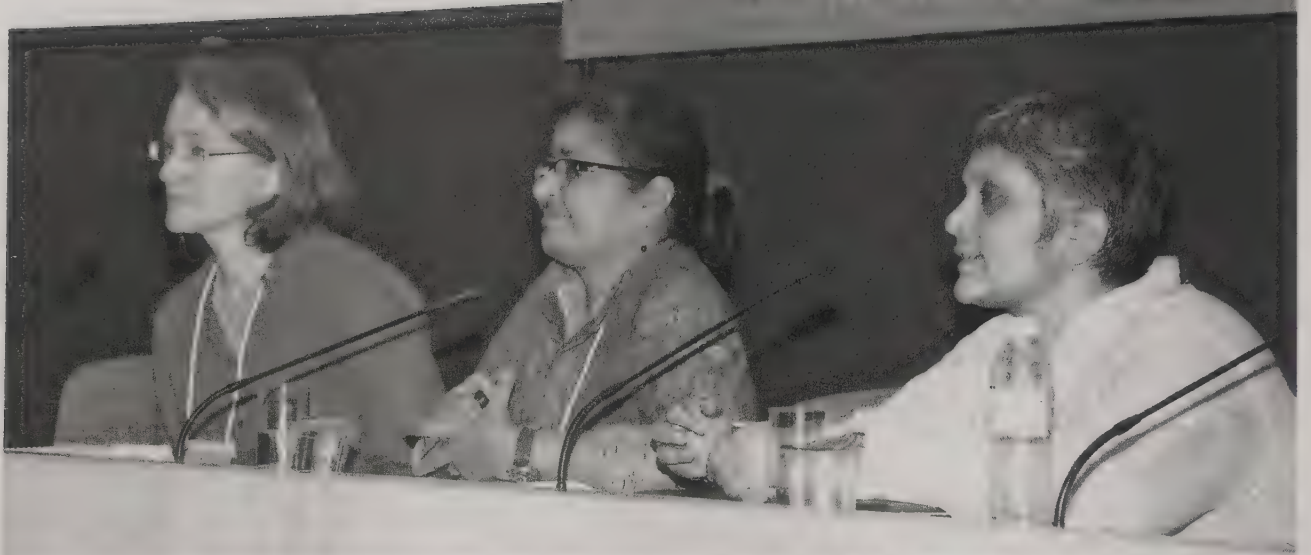








# Sama - Resource Group for





# Emerging Perspectives and Challenges: Towards a Global Movement

Coordinators: Sandhya Srinivasan and Jyotsna Agnihotri Gupta

- There is a need to identify *feminist political strategies* that can accommodate the diversity of country experiences with ARTs, as highlighted by the presentations from South Asia. While examining the issue of ARTs, connections need to be drawn with old feminist debates on abortion, adoption and sex work. What are our positions on these issues in relation with ARTs? The feminist movement in India has been confronted with the sudden rise of 250 fertility clinics. ARTs are no longer being accessed only by a minor, elite cohort. Although issues of population control have been the focus of feminist struggles in India, and are important even today, India's strong women's health movement now needs to expand from contraceptive to conceptive technologies. We need to decide on certain non-negotiables, which will work as a framework for reviewing our strategies. We need strategies within the movement, and vis-à-vis the state, industry, etc. Given that patriarchy will not go away in another 100 years, the question is what can women do in the interim? Let us not throw the biotech baby out with the bathwater, and see how we can use bio-technology for collective betterment.
- *Regulation* (and the lack thereof) is driving ARTs globally, because when a technology is unavailable in one country, people

simply travel to another country where it is available. Given the specificities of each country, we need to think more critically about blanket positions, particularly with regard to regulation. Is regulation the way to go? What regulation means, and the way it is put into practice, is radically different in every context. Does putting a regulation in place, even if it is not a pro-business one, mean anything in terms of practice? Although abortion is illegal in almost every nation in Latin America, it has the highest abortion rates in the world. We need to be as specific as possible while thinking of the kind of activism that will be useful. All over the world, there is a trend to leave regulation to the market. Vested interests are rapidly infiltrating regulatory bodies and drafting committees for regulation bills, like with Monsanto in GEAC (Genetic Engineering Approval Committee) or with baby foods. This is linked to the issue of IPR and bilateral 'knowledge' initiatives. Where do we need to direct maximum energies in dealing with these issues? Further in India, where primary health care services are dismal and the most basic regulatory laws in the health sector are not implemented effectively, how do we ensure that regulation on bio-technology will be any different? Will having an Act, even one that is to our acceptance, be able to tackle the misuse of technologies? Therefore, while it is absolutely urgent to work for

regulation, it is also important to realise that regulation alone is not sufficient. We need regulation to address certain issues, and need to stress that the social aspect of these issues cannot be left to the market. We need to view ARTs through the same lens of critical analysis with which we view other powerful technologies, like big dams and chemical pesticides.

- The issue of *patents* has a direct impact on commodification in biosciences, genes, genetic modification, GM foods and so on. The general understanding in WTO circles is that the inherited property of humankind cannot be patented.
- We need to think of how we can explicitly open up the *family* as a site for feminist struggle. The problems that stem from infertility particularly begin with the family. Some old philosophical issues are also coming into play here. Patriarchy has always deployed notions of immortality and immaterialism, of which afterlife, reincarnation and the production of children are all part.
- The recent *Law Commission Report* on the ART Bill in India mentions that a woman is respected as a wife only if she is the mother of a child, so that her husband's 'masculinity' and 'sexual potency' are proved, and the lineage continues. This is the state's ideology behind the ART Bill, with respect to women's roles. With respect to surrogacy, it also mentions that one of the intended parents should be a donor as well, because the bond of love and affection with a child primarily emanates from a biological relationship. Further, the chances of various kinds of child abuse, which have been noticed in cases of adoption, will allegedly reduce if there is a biological relationship. Such documents must be kept in mind while strategising about the constitution and possible reconstitution of the family.
- ARTs challenge and complicate our understanding of concepts like *citizenship* and *parenthood*. How are sperm and ova donors positioned in terms of the identity of the IVF child who emanates from their biological material? They certainly do not figure on the promotional material of IVF clinics, which invariably show a heterosexual couple with a baby, though the genetic inheritance of that baby may be from elsewhere. So who is the parent? In the Draft ART Bill, IVF clinics are legally prohibited from divulging information about biological parents to the child, even when she/he is an adult. Is this not a violation of her/his rights? Another interesting complication is that citizenship rights are not granted immediately to babies born to Indian surrogate mothers. There is a tension here, wherein the state wants to promote medical tourism, but does not want to grant citizenship to 'foreigners', including to Bangladeshi nationals residing in India.
- There are differences of opinion on the legitimacy of *surrogacy* as an option, so should surrogacy be brought within the ambit of discussions here? In discussions, some rural women from Tamil Nadu have expressly said that they do not want a blanket ban on surrogacy, and have made a distinction between altruistic and commercial surrogacy. Perhaps the issues around technology cannot be collapsed with the issues around surrogacy at all, as is the tendency in the media and the ART Bill. The latter debate is similar to debates around sex work, labour and reproductive labour, and raises questions about the choices and the vulnerability of participating women.



- While the discussion has been focused on the supply side of ARTs, we need to talk about the *demand* side as well – size of the market, perceived need for ARTs, and other alternatives for assisted reproduction (traditional medicine, *gurus* and *dargahs* for instance). It cannot be denied that childlessness is a big problem, and it would be partial to say that it is created completely by corporations.
- A lot of work needs to be done to build *awareness* – about safe period, perceived infertility, male infertility (which is more than half of all infertility cases), etc. Public education campaigns can go a long way in taking some of the burden of fertility off women in marriage. In Egypt, a new marriage bill mandates pre-marriage semen analysis for men. The ongoing debate on making sex education part of school curricula assumes significance here. However, sex education, which would be able to fill the existing knowledge gaps that contribute to infertility and the demand for ARTs, is being opposed on religious grounds. Public education is also required in order to counter the distortions and baseless claims of clinics circulated especially through the internet. Sources of information, like registries, need to be made available to women before they opt for the ART procedure. While the CDC (Center for Disease Control) in the US does collect data from clinics, it is very minimal and inadequate. Clinics often get exclusive and restrictive about who they will treat, in order to have a higher success rate for projection later. The CDC registry is voluntary, with no penalties for non-compliance. Younger people, particularly, need media literacy training so they can learn to be critical about the sources of the information they receive.
- A lot of infertility is amenable to simpler methods of treatment. Given that there is mainly secondary infertility in the third world, it is *primary health care* that needs strengthening. Yet, the state cites the ‘needs’ of women to promote big business. Today legislation is an instrument to promote corporate interest. We need to bring in capitalism when we talk about patriarchy, and we need to bring in men when we talk about reproduction.
- We need a *multi-pronged strategy* that will work at different levels - the state needs to be engaged legislatively, younger people need to be given information, and the struggles of the working classes for livelihoods, dignity, survival and women’s rights, need to be supported. Media interventions through the news and TV serials, as well as ethics in medical education are areas that need examination and work.
- ARTs, surrogacy and ‘donations’ need to be seen in the *context* of the tissue economy, wherein risk is manufactured to sell a kind of biological insurance. Today there is a ‘digitisation’ of the body going on, related to patents and property rights over children, adoption, lineages, etc. Genetics has implications for what our duties and responsibilities are, because not only does it seek to create the ‘perfect’ human being, but also to encompass all that we are in life.

# Global Experiences: South Asia

Coordinators: Padmini Swaminathan and Betsy Hartmann

## **'Doctor's Babies': The Scenario of Unregulated Trade over Infertility in Bangladesh**

*Farida Akhter*

Fertility has always been linked to the population issue and considered a problem in Bangladesh. The last population census in 2001 put the figure at 130 million. Population data varies from source to source. Current estimates are in the range of 140 and 160 million people and these large numbers are seen as the cause of many problems, including floods! Contraceptives are seen as the solution and there is a constant search for new methods along with forced sterilisation, and the use and abuse of population control methods. Women have been used as guinea pigs for all population control methods right from the sixties – pills, IUDs (Intra Uterine Devices), sterilisation, Depo-Provera in the eighties, menstrual regulation, Norplant testing, Quinacrine, RU 486, etc.

In the backdrop of 'burgeoning population', it was always considered that IVF will be irrelevant for Bangladesh. Ironically, the country has gone from fertility control to promotion of infertility management using ARTs. Infertility is viewed as 'bad luck' for married couples and is considered the woman's incapacity or failure. This has to be seen in the context of men marrying women in order to have children (preferably male)

who can inherit property or be a part of the family occupation. A married woman's job, therefore, is to deliver a male baby. This is the demand side of ARTs.

Although there are no official statistics, doctors in the business of ARTs have started coming up with some baseless figures. Couples that do not have a baby after five years of married life, despite wanting to have one, are identified as 'infertile' and the doctors claim that there are over 3 million identified infertile couples, which is 10 to 15 per cent of couples in the country. Advertisements of clinics talk about technology bringing 'hope' for infertile couples. The image used in such communication is always of a fair, blue-eyed baby boy.

Clinics have also started talking about male infertility because it means more business. Socially, however, women's infertility is still the issue. Men marry more than once in their efforts to have a baby. Women face divorce or have to accept polygamy. That is why women prefer to get treated for infertility.

According to Bangladesh Fertility Society and Harvest Infertility Care Ltd., the causes of infertility are many: drug addiction, environmental pollution, irregular menstrual cycles and delayed marriage; the use of detergent powder, chemical fertiliser, pesticides, use of preservatives in food, excessive use of plastic materials, among others. Thus, there is a strong link between



the infertility industry and other related industries, like food production.

There are increasing number of cases of miscarriage, deformed babies, complicated pregnancies and other gynaecological complications in villages due to exposure to pesticides. However, neither these issues nor other reproductive problems are addressed.

Since the early 2000s, a range of ARTs (IVF, embryo transfer, frozen embryo, ICSI, IUI, etc.) have been used and more than 479 babies are said to have been born. Over 20,000 couples have sought treatment in different clinics so far. However, the treatment is marked by poor consultation and discussion between patients and doctors. The doctors, trained in Singapore, UK, US, India and Australia, are offered joint venture funding and assistance from other countries.

There is no follow up with parents who have undergone treatment or counselling about the risks and dangers to the child or to the woman's body. Most often quadruplets die after a few days, but the only cases that make it to the news are the 'successful' ones. Once the baby is born, all credit goes to the doctor, hence, the term 'doctor's babies.'

The birth of Hira, Moni, Mukta, the first test tube babies (triplets) born through IVF (in 2001), as well as their birthdays every year are celebrated by the media. Their parents, Abu Hanif and Firoza Begum were delighted to have them after 16 years of their marriage. They paid Taka 200,000 (70 Bangladeshi takas equals US \$ 1) for the treatment. After the birth of the babies, they were kept in incubators for close to a month, costing them Taka 7,000 everyday. Today they say they cannot make ends meet to raise the three children.

Dr Rashida Begum, an infertility management specialist known for using frozen embryo

technology, makes it clear that only those who are strong enough to accept failure must seek treatment. She compares infertility treatment with a lottery: "you can try with equal chances of winning or losing". The cost of her treatment is around 80,000 Taka.

The trend has been of a larger number of girls being born than boys. In one clinic, out of 26 cases of test tube babies, 17 were girls and nine were boys. Among quadruplets three out of four babies are girls; most twins are girls. This exists simultaneously with the wide use of this technology for sex determination. Although the general trend is towards seeking a male child, infertile couples are happy to have even girl children since it helps them overcome the stigma of infertility.

In a time span of five years, IVF clinics have been growing. Dr Parveen Fatima, who was instrumental in the birth of Hira, Moni and Mukta in 2001, was employed as an Associate Professor in the Department of Gynaecology and Obstetrics in a government hospital, but soon she opened a private clinic – Centre for Assisted Reproduction (CAR). She started the clinic without any equipment, trained personnel or technical know-how.

Just as in family planning, which started with the middle class and was considered empowering and then included the poor through coercion, there is a class issue in infertility management too. Middle class couples can afford to pay for treatment, whereas the poor sell assets to access it.

The commercialisation of the technical solution to infertility means that profits are being made by exploiting the desperation of women. The question is whether this is really infertility treatment or merely another business. Since the component of 'assistance' is in doubt, should we continue calling these technologies *Assisted Reproductive Technology*?

## Unraveling the Fertility Industry: ARTs in the Indian Context

NB Sarojini

ARTs are becoming a standardised procedure for bypassing infertility, although it is still a trial and error method, leading people to go for innumerable cycles of IUI, IVF, ICSI, IUI followed by IVF, IVF followed by ICSI. In the absence of a national registry, it is difficult to provide accurate statistics about the number of infertility clinics. Recent media reports claim that there are 350 ART clinics in the country. The number of registered infertility clinics is said to have gone up four times in recent years. There has been a steep rise in the membership of ISAR (Indian Society for Assisted Reproduction) from 184 members in 1997 to 600 members in 2005, which is, no doubt, a conservative estimate.

The reach of ART clinics is no more concentrated only in the metros and big towns but is also reaching those semi-urban townships and rural areas which lack basic civic amenities and other necessary health care facilities. ART clinics are varied in terms of appearance, outreach and facilities, depending on the locale and the clientele they cater to. They are housed in shabby places with inadequate infrastructure (when measured against guidelines of the ICMR), without backup electricity facilities and proper laboratories; at the same time there are clinics which are housed in corporate hospitals in flashy up-market areas.

Hence, it is futile to talk about a generalised fertility industry and it is important to make it clear at the outset that this fertility industry is as diverse as any other industry. Commercial surrogacy and egg donor programmes are becoming an integral part of this industry.

Capitalist endeavour has always used patriarchal normative ideology to the best

of its advantage. The proliferation of ARTs is one of the best examples where state-of-the-art facilities have been marketed with the justification by providers that it is the 'need of the hour' and that they are merely responding to the market demand, precisely the demand of 'desperate women' to become mothers. As an IVF provider puts it, "*people have to want something for it to survive in the market*".

Providers have been exploiting the existing stigma, ridicule (whether subtle or apparent) and violence against women due to infertility. There have been instances of women facing violence, being denied their ancestral property, and husbands remarrying. Absence of or poor basic preventive infertility care in the public sector even at the tertiary level has also promoted the growth of ARTs in the private sector.

While basic health services are almost nil or are rudimentary, two government hospitals in Delhi have started offering state-of-the-art ART facilities. The logic of developing countries serving as destinations to procure goods and services at cheap rates has been extended to the fertility industry; what is bought and sold here is reproductive material and reproductive labour.

As in the case of any consumer product, the fertility industry is marketed by aggressive advertisements to draw couples with promises of fulfilling dreams through taglines like:

*'The Miracle of Life...In-Vitro Fertilisation...  
We make your dreams come true...'*

*'When desolate homes resonate with children's  
laughter...'*

*'500 childless couples have achieved  
'happiness'.*

Advertisements can be found on websites, fancy brochures, on walls and hoardings on



streets, at bus stops, near adoption agencies and local cable channels.

Lucrative bargains for egg and sperm donors and surrogates are seen even in newspaper classifieds:

*'Wanted healthy lady, age 20-35 years. Unmarried/married widow lady to bear child for childless family through artificial insemination or IVF. Earn Rs 50,000 - 60,000...'*

Partnerships have been forged between well known clinics (doctors) in metros and big towns and upcoming clinics in semi-urban and rural areas. New schemes have been developed to survive the competition in the market like, money-back schemes, camps and service in batches. Camps and IVF in batches are becoming the specialty of semi-urban clinics, which depend on 'mobile embryologists' and 'flying doctors' (coming from bigger cities). Discounts are given for on-the-spot registration in an effort to beat the competition. IVF providers claim that they offer the third or fourth cycle free for patients who cannot afford them. In return they hope that the clinic will be recommended to others.

The fertility industry is an integral part of the growing medical tourism industry, which is supposed to bring additional revenue of US \$ 1-2 billion by 2012 and is being seen as a new avenue for drawing foreign 'traveling' patients and Non-Resident Indians (NRIs). A typical 'medi-tour' would offer a combination of a therapy or treatment and recuperation at places of the client's choice. The recuperation would often include popular tourist activities. Such 'Special Care Packages' include providing facilitation letters for obtaining an Indian visa, designing pre and post holiday itineraries for the clients, a support system and human contact at all times during the

client's treatment in India, including services of a nurse or guide (if required).

India has been termed as the 'mother destination' for drawing large numbers of couples for commercial surrogacy. The country's rapidly growing commercial surrogacy industry is worth US \$ 445 million per year. Anand, a town in Gujarat, has become the epicenter of the commercial surrogacy industry in India. We can see an emergence of surrogacy centres and hostels for surrogates and surrogate agents. A centre in Chennai claims that there are 15 cases of surrogacy every month.

New players, including franchises and law firms, are entering the market, like Proactive Family Solutions, Mumbai, which is a wing of BestMed Journeys, Florida; Rotunda, Mumbai, which is linked to Planet Hospital, California; Indian Surrogacy Law Centre, Chennai, etc. One of these firms said that in the last year, about 27 couples registered at the US office. This essentially means that about 27 couples are now at different stages of the surrogacy process and are paying Rs 0.6 - 1 million in three to four installments.

The key reasons for India's dominance include:

- Lower costs (a fourth of the cost in the West);
- Large top-notch private health care providers;
- English-speaking providers;
- A socio-political climate that encourages the outsourcing of Indian labour;
- Existence of world-famous tourist destinations;
- Large number of women willing to engage in surrogacy;
- The total absence of government regulation.

ART providers give the justification that commercial surrogacy is opening up new avenues for women to earn money. They say that it is unfortunate that this is receiving an undue share of negative publicity. "Anyway women here normally have four to five children. If she acts as a surrogate once then what is wrong? She can earn Rs 2 - 2,50,000 from one surrogacy, and her family can get settled".

However, there are market anomalies that operate in health care and the standard competitive model does not apply to this sector. The lack of standardisation in treatment protocol is especially acute in ARTs leading to multiple trials based on how much a couple can afford to pay. Health risks associated with these procedures are projected as insignificant and safety regulations are minimal. Varied and exaggerated success rates are claimed to woo patients. Clinics consider a positive pregnancy test as a 'successful case' ignoring any complications that may arise later, even the child not being born.

There is no standardised cost structure for ARTs and the variance is not only in procedural costs but in those of drugs as well. The cost of IUI varies from Rs 1,500 to Rs 10,000 and of IVF varies from Rs 75,000 to Rs 150,000.

Informed consent is a mere formality in ART treatment and there are cases of sex selection, multiple embryo implantations and of post-menopausal women having children. An ART provider justifies using multiple embryos by saying that they want to increase the chances of implantation. "Countries where only one embryo is used are those where the government sponsors IVF cycles".

Given the market scenario, the natural question that arises is who is the consumer. A media report in 2007 claims that women

and men from all sections of the society and even the remotest parts of the country are seeking treatment as are NRIs. Sama's study also indicates a wide range of individuals who have accessed ARTs. In fact, although the technologies are accessed primarily by the middle and upper class, the lower rung of the population is also making an effort to use it. The respondents include NRIs, IT executives, hoteliers, on the one hand, and landless farmers, daily wage earners, on the other.

Although the technology is expensive, it is said to be affordable for all classes, and is even being justified by comparisons with wedding expenses and the cost of heart surgery! There is evidence of people taking loans, selling assets, and being 'broke' after repeated failed cycles or after having a child. Nonetheless, respondents have said that they will go to any extent to try to have their own child.

Moreover, while this industry is modeled and operates largely on the lines of a capitalist manufacturing industry, its legal, political and ethical implications, within the country and beyond, are still unfolding.

Hence, there is a need to initiate a discussion on strategies and plan collaborative research and advocacy at the national and international level. Alongside, a strong community-based approach is essential because no advocacy can bring the desired result if it is only at the level of the market.

In India till today, there is no legal mechanism in place to regulate the fertility industry. The guidelines of the Indian Council of Medical Research (2005) are not legally binding. The draft ART bill (2008), with its innumerable shortcomings is yet to be finalised. A central registry or any other such mechanism needs to be put in place to monitor ART clinics and provide data on the number of ART clinics and their outcomes, the number of cycles,



failed cycles, live births, the sex of the child born, the number of surrogacy cases, etc.

There is a need to ask questions about the measures to ensure women's health and safety in a context where there is a lack of systematic research on the health implications of drugs, the invasive procedures used and a concomitant suppression of existing literature highlighting side effects.

### **Experimental State, State of Experiments: State, Science, Citizens and Embryonic Stem Cell Research in India**

*Aditya Bharadwaj*

Assisted conception technologies and stem cell technologies are so completely intertwined that separating one from the other has become difficult.

The notion of the 'experimental': In scientific parlance, an 'experiment' would typically entail a test or procedure carried out under controlled conditions to determine the validity of a hypothesis, or to make a discovery. At its broadest, an experiment is an invitation or an opportunity to try something new. Specific sites within Indian bio-technology that seldom get articulated as experimental range from the micro or bio-genetic, e.g. human gametes and embryos, to infertile women or men as macro anatomical sites for extraction of such bio-genetic surplus, to the role of the Indian State's experiments with legislations, bioethics and IPR. In India, these sites seldom get capsulated as experimental, save in the activist discourse, because they are either enunciated as consent, choice and contract between the state and the citizen or as pure epistemology and untainted science. This is achieved without ever explicitly marking the infertile body's spare embryos' commercial, clinical and research interests as experimental sites and subjects. On the contrary, the ethical,

legal framing of human embryonic stem cell research in India, has all but displaced the governance of bio-technology of these stem cells into the realm of the experimental. It is within this emergent neo-liberal reasoning that the burgeoning growth of assisted conception and embryonic stem cell technologies are flourishing. In reviewing the experimental state and the state of experiments in India, two sites have to be grappled with that both, facilitate and produce, human embryonic materials; the Indian state's experiments in governance and broadly defined, the state of scientific and clinical experiments in pursuit of knowledge, commerce and profit.

There is a fundamental shift from the capitalist mode of production to a neo-liberal mode of production. While the capitalist mode of production is preoccupied with concerns around managing waste, in the neo-liberal mode of production, the concern is predominantly of recycling the waste, to ensure that nothing goes waste. Therefore, citizens and sites that were previously considered and articulated as wasteful and dispensable are suddenly becoming a rich resource to be harnessed in some straightforward way, and for their tissues and body parts to be liquidated and fed to the booming neo-liberal economy. So it is a win-win situation as far as the state is concerned. Yet, there is little to say about the social and economic inequities that distort real economies.

In neo-India today, women's reproductive potential has come to be viewed as both a scourge - most graphically illustrated in the aggressive and gendered nature of population control policies pursued by the state - as well as a boon in the shape of reproducers of the Indian state and the economy itself. In great measure neo-India owes its rise to the army of its young workforce and a reserve pool of its staggering 500 million people under the age of 19. In this respect, by fulfilling

their patriarchal requirement, set within the parameters by the state, Indian women make their reproductive labour valuable in the neo-liberal mode of production.

To achieve an ethical and steady supply of human embryonic form (for participation in the global moral economy), the Indian state has embraced guidelines that are largely inspired by regulatory frameworks in the UK and US, thus renewing the focus on women. So there is an ironic shift from 'too many babies' (family planning, two child norm) to 'no babies', and in the new century, infertile women and their technologically induced oocytes and embryos are rapidly becoming state subjects in need of regulated development, production and most importantly circulation.

The language of gifting and altruistic renunciation of human tissue is well established in the bio-medical and bio-ethical discourse. The most notable insights have emerged from studies examining the global transactions in human organs such as kidneys. Nancy Scheper-Hughes argues that the language of gift, donation, heroic rescues and saving lives masks the extent to which ethically questionable and even illegal means are used to obtain the desired object - kidney, or even embryo. The sacrifice is rendered invisible and hidden within the rhetoric of 'life saving' and 'gift giving'. The case of embryonic gift however, is more complex, as it cannot be simply recapsulated as a mere gift of life, but rather in the case of embryonic stem cells, as a gift of potential knowledge to a medical researcher. This is knowledge that produces value, through not mere circulation, but more significantly through transferal into a derived self product, with accompanying claims to intellectual property and ownership detached from the point of embryonic conception.

The gifting of spare IVF embryos in India, in line with the prevailing practice in other

global locales has hastened the creation of citizens who, from the point of view of the state and its legislative modalities, can be imagined as imbued with individual rights and possessing bodily autonomy, who, in turn, can be made well informed to consent from a position of knowledge and courage to make choices reflecting free will. Not too dissimilar assumptions are implicit in the arguments favouring open commercialisation of organ trade around the globe. How might this critical frame help contextualise this deeply cultural and socio-economic issue at stake in securing consent, contract and choice in embryo donation in India? This is especially sensitive when we pause to consider how infertility or reproductive disruption on a similar scale is a profoundly disabling condition, especially in the context of classic patriarchy, privileging and conflating motherhood with womanhood, and fatherhood with manhood.

However, ever since the bio-technology of embryonic stem cells became thinkable, the stifled 'potentiality' of reproduction has attracted both public and private sector attention in India. This is most graphically illustrated in the proposed ethical guidelines of the ICMR, on infertility management and embryonic procurement, which has created a furore in the medical community in India. The main bone of contention in the ICMR guidelines is the proposed prohibition of intra-familial gamete donation. The medical community has reportedly taken strong exception to the ban on sperm donation by a relative or a known friend of a wife or husband, fearing that this will trigger paid donation and trade in semen. Some fertility experts and stem cell research scientists are fiercely opposed to this legislative move and for good reason. Should this guideline become a law, the consequences of such a move may in fact impact on family forming strategies employed within the confines of a clinical space, where tactical alliances are formed between select



family members and clinicians to keep family forming as close to kin blood as possible.

The question arises as to why the Indian state is inserting the market and contractual commercial transactions into a domestic moral economy of exchange and kin relations. In many instances, intra-familial exchanges are modern ways of doing tradition; negotiating with patriarchal, gendered and religious injunctions while conforming to the pro-natalist imperative. The neo-liberal state in India is however seeking to outlaw these practices for reasons far more complex than mere social reform and protection of women from the excessive demands made by the patriarchal, ideological order. On the contrary, the new laws hold the potential to create a body of medicalised, childless citizens that can be both harnessed and garnered for extracting embryos, gametes, etc. to fuel the burgeoning global moral economy in stem cell creation. By putting in place strict informed consent procedures, instituting a further national ethics committee and ensuring the provenance of any potential lines accruing from human embryos, the Indian state is seeking to isolate the ethical sources of producing raw material. These ethical sources are imagined as fully informed, rational and autonomous consumers seemingly liberated by the market from the fetters of out-moded and traditional reliance on familial support for assisting life. These autonomous citizens can now be enjoined to sacrifice their bio-genetic spare embryos with the encrypted provenance in the service of a neo India.

Margaret Lock explains how the procurement of human material to make immortalised

cell lines was fostered by two international agreements, Convention on Biological Diversity and GATT, TRIPS Agreement, now the WTA<sup>3</sup>. These international agreements were made legally binding in 1993 and 1994 and led to the globalisation of intellectual property laws. This meant that individuals who donate their own body parts for research purposes, do not retain property rights over certain materials nor can they participate in any profit that may result from the manipulation of these materials. Lock describes a case where the US government made a patent claim on a cell line created out of blood taken from a 26 year old Guaymi woman suffering from leukemia. Similar patent claims were made on cell lines obtained from several Hagahai and New Guinea and native Solomon Islanders. The Hagahai reportedly agreed to blood donation subsequent to the creation of cell lines and their patenting, on the condition that individuals claiming Hagahai ethnicity would share half of any resulting profits from a vaccine or any other bio-product. However, all patent claims on Hagahai and Solomon Islanders were eventually dropped as the resultant stem lines were deemed unprofitable to pharmaceutical business. The above cases provide a useful point of departure to better contextualise the emerging bio-politics of embryonic stem cells in India in which infertile citizens and their bio-genetic capital are being invested with a promise of future returns.

The ICMR guidelines on stem cell research declare that research on stem cell lines and their application may have considerable value, and that appropriate intellectual property rights protection may be considered

<sup>3</sup> The World Trade Agreement (WTA) is a multilateral trade agreement consisting of a number of specific agreements on various issues relating to trade. The present agreement is the result of a series of negotiations during the period 1986 to 1994 as part of the Uruguay round of GATT negotiations. TRIPS was negotiated at the end of the Uruguay Round of the General Agreement on Tariffs and Trade (GATT) in 1994. Its inclusion was the culmination of a program of intense lobbying by the United States, supported by the European Union, Japan and other developed nations. (<http://www.vuatkerala.org/static/eng/wta/wta/structwta.htm> and [http://en.wikipedia.org/wiki/Agreement\\_on\\_Trade-Related\\_Aspects\\_of\\_Intellectual\\_Property\\_Rights](http://en.wikipedia.org/wiki/Agreement_on_Trade-Related_Aspects_of_Intellectual_Property_Rights))

WH-105

PIO

on the merits of each case. If these rights are commercially exploited, a proportion of benefit shall be ploughed into the community that has directly or indirectly contributed to the IPR. Community here includes all potential beneficiaries such as patient groups, research groups, etc. which is an interesting point of departure.

Though seemingly far-sighted, there is a morality of another kind at work in the economic calculation of the Indian state, namely, how might the informed citizen be enrolled in the production of knowledge which is both promissory and profitable. The projected benefits are two-fold: first, they offer hope for cures for a spectrum of disorders and, in that respect, the renunciation of a spare embryo is a worthwhile investment. Second, the promises of future returns are made tangible not merely as a therapeutic breakthrough, but by building commercial and economic stakes into the gift itself. The contract with the state through consent is predicated on the creation of a citizen imbued with the will to choose morality and profitability, as opposed to donate with the hope of alleviating suffering. Thus, there seems to be a fundamental shift here from being altruistic to being commercial. Nevertheless, despite the official interest in IPR and profit-sharing, it would not be at all surprising if in making a transition from knowledge to practice, from science to commerce, the IPR issue is dropped altogether, as logistically, commercially and economically untenable, especially as more private capital (as opposed to state investment) flows into bio-technologies.

The question is: why is this problematic and why does it have potential for more trouble than it is worth? Predominantly because human embryonic stem cell research in India as a private initiative is

a disturbing, new, emerging trend for all classes of people. There is a new modality of offering IVF treatment emerging in India - 'spare IVF cycles for spare embryos'. Often working class people from small towns and villages are made offers of free IVF cycles if they agree that spare embryos will be created or spare oocytes will be used for human embryonic stem cell research. However, in its desperate hurry to get into an ethical embrace with the Euro-American benchmark of what an ethical practice might look like, the Indian state has done a spectacular cut-and-paste job, mostly from the HFEA, in their proposed guidelines, where only spare IVF embryos are seen as a legitimate source for human embryonic stem cell extraction.

When 'ethical embryo' is construed in that light, it doubly implicates an IVF treatment seeker in very straightforward ways. On the one hand, these women are trying to escape unbelievable social ostracism and stigma - a lot of them are in these clinics with very profound stories of suffering and complete and utter social delegitimation. In such a context, the citizen is somehow enjoined to come up with a free and informed choice regarding whether she would like her embryo to be used for stem cell research! Globally, such a donation is repackaged as ethical, informed and consented and becomes the ethical basis for an embryonic stem line whose provenance is squeaky clean and ethically audited.

To conclude, the Indian state is involved in a collusion with infertility clinics to an extent that is making access to human embryos that much easier and more straightforward. Of course, there are larger global politics behind these laws, which are not so much for the protection of human subjects but for the protection of commercial interests.



## Coordinators' Comments

### *Betsy Hartmann*

- IVF camps bear a striking similarity with sterilisation camps and are a reminder that the parallels and intersections of population control and ARTs have to be assessed strategically; both in terms of success and failures, in different contexts as well as internationally. We should draw on our history as the international women's health movement in fighting population control. In the neo-liberal economic context of today, the basic issues of informed consent, safety risks, etc. are being articulated again.
- The range of clinics and the variety of their clientele is a new characteristic. This raises issues of research and experimentation on women's bodies, especially the use of spare IVF embryos for stem cell technology. We need to call attention to the nature of 'experiment' at multiple levels.
- Even if we cannot aim for accurate registry, we need to be clear what kind of transparency we are looking for.
- There is a need to draw trans-nationally on movements that have critiqued and changed international agreements for regulation.

### *Padmini Swaminathan*

- While examining the ART industry, the perspective of its 'demand' side also needs to be taken into account.
- We need to understand how the ART industry is located within population control, and the dynamics that have made South Asia the hub of both, overpopulation and infertility.
- How do we view and analytically segregate the different nodes of

these value and supply chains, and where do we focus our collaborative research efforts?

## Discussion Points

- Although there is a suspicion that poor Bangladeshi women are being taken, even trafficked, into India for surrogacy, there is as yet inconclusive information on this front.
- One of our strategies has to be the critique of text books for medical students, especially forensic medicine. The ideas of citizenship, ownership, body parts, etc. have to be examined closely here. Further, there is no reliable public information on the health risks of pesticides, GM foods, or ARTs. There is a risk of ovarian cancer (after repeated fertility treatment), multiple gestation, miscarriage, tubal pregnancies and their recurrence; all of which need to be highlighted, especially for informed consent. We must not repeat our mistake in the general health sector, wherein neglect of the public sector leads people to the private sector.
- The attempt to control the seed— be it in the plant or in the womb— has to be challenged. Yet we cannot lose sight of the real causative factors of infertility. Infertility has to be seen both, as a psychological state as well as a real condition. The fertility industry is up and running because it is more demand-driven than supply-pushed. Women turn to these technologies to ensure their survival within patriarchy. Is it our job to tell these women that they are living under a Marxist 'false consciousness', and to then 'educate and empower' them? Does that not set up a different kind of hierarchy? Nonetheless, demand also cannot translate into a case of 'out

of the frying pan, into the fire'. Women should not need to go from quacks to irresponsible medicine to address their fertility needs. Legislation must be put in place to ensure some degree of control and responsibility. For instance, a Karachi clinic is now advertising embryo screening, which costs GBP 1000 and has no proven scientific value. It is just a gimmick to screen and test embryos for huge sums of money, only to say later that the embryo is not good enough.

- It is ironical that the Indian state is interested in promoting ARTs to create a larger workforce when it already has one. Perhaps, the point of departure for the state is not the amount of investment (which is not very high), but the state's manifesto and the need to lead the world in bio-technology. The state wants to align itself with the global north politically, ethically and ideologically. Former Prime Minister AB Vajpayee is on record as saying 'IT is India Tomorrow and BT is Bharat Tomorrow', symbolising this shift with a slogan that really captures public imagination. There is an international moral economy that necessitates the creation of ethically-sourced products for guilt-free, untainted consumption, be it fair-trade coffee, child labour-free carpets or consented embryos. Ethics are now being factored in as necessary costs, alongside labour, etc. that must go into the production process, and in this neo-liberal consumption model, we are all implicated to a larger or lesser degree.
- The family needs to be opened up for critical scrutiny. The 'mother' requirement has not shifted from the woman. Stories of suffering of infertile women make us think that maybe they should have access to ethical, regulated, quality ART services. However, there is a

need to learn from earlier struggles that seemed equally implausible at the time, but were necessary and later, successful. For instance, in Africa, opposition to female genital mutilation was successful only when it was taken up by African women themselves, and not when it was proposed by outsiders. Perhaps, there is some lesson for us there in our efforts to oppose ARTs.

- Population control is not only about numbers. It has eugenics, racism and other dimensions built into it, all of which are also part of ARTs. Reproductive technologies are even being promoted in advertisements as a better alternative to natural birth; because fathers can be completely sure of their baby's paternity in ART treatment!
- On issues of population control and sex-selective abortions, feminists have gladly functioned against the state. To be able to broad-base our campaign, we brought in health activists and other groups that were questioning the state, but often sharp feminist perspectives and discourses got left out. We tend to find commonality as long as we think of women as victims, but we find ourselves at a loss when we confront women as agents. The scenario today is no longer one of male doctors, male researchers and poor women, but really one of women clients, women doctors, surrogate women - all apparently happy with the IVF industry. In such a scenario, how do we bring the family into interrogation - particularly on issues of biological motherhood, couples without children, single women and so on.
- We must recognise the divisions within the women's movement, and the co-option of feminism by international funding agencies. There is a need to honestly



assess the outcome of our battle against unsafe contraceptives. The oppressive conditions under which Depo Provera was being delivered have changed, but (the market for) Depo has in fact proliferated. If anything, activist language has been co-opted and contraceptives are now being promoted as sensitive to culture and women's needs. In North America today, young women do not even see this as an issue, and instead support Depo Provera and Norplant.

- Further, in India the high percentage of sex-selective abortions leads to a rich source of germ cells. There is a need to look into how aborted fetuses are being used for stem cell research.
- Capitalism is a versatile beast that mutates at a great speed, and our discourses and responses need to respond at the same pace. In our language of resistance, should we call these technologies 'Assisted' reproductive technologies at all?

# Global Experiences: Middle East

Coordinators: Malini Bhattacharya and Aditya Bharadwaj

## Ova Donation Bill: the Israeli Case

*Hedva Eyal*

The Ova Donation Bill in Israel is in the final process of legislation. It will allow ova donation from donors who are not undergoing fertility treatments for the purposes of reproduction and stem cell research. The proposed legislation is a result of the unification of two separate legislative documents: the Ova Donation Legislation, and the Genetic Interference Prohibition Act (related to Human Cloning).

In Israel, IVF treatments are given free of cost to citizens until they succeed in having their first child. The public health system strongly supports fertility treatments, which are considered to be a basic right of women. This creates a situation in which women who are unable to conceive 'naturally' are more or less automatically urged to go in for IVF treatment, without being given the space to think about the consequences of the treatments for themselves and for donor women. A woman's decision to not undergo the treatment is considered highly irregular.

The main actors of the Ova Donation Bill are:

- Doctors and researchers, who portray their efforts as those that are for the benefit of women and declare that women's groups are anti-progress and anti-science.

- A group of women in Israel who have come together because of their need for egg donation.
- Rabbinic authorities, who stress on the concept of 'mitzwah' i.e. the need to increase the Jewish population in the world.
- The organisation Isha L'Isha feels this is an opportunity to delink womanhood and motherhood and look at issues of trafficking. When they began looking at the new ova donation Bill it had already been through the first hearing.

The main concerns with the Bill include its failure to appropriately address the significant health risks involved in the donation process. It makes provision for basic health insurance, which does not cover future health complications. It overlooks the economic exploitation whereby young, local women are donating eggs.

In Israel, egg donors do not necessarily belong to the lower socio-economic strata but are mostly young women, looking for an alternative means for further improving their economic status. The proposed Bill allows for structural conflict of interests between doctors and donor 'patients', without considering the implications of such conflicts. The Bill overlooks the possibility of conflict of interest wherein the same doctor takes care of a woman who wants treatment,



of one who is donating eggs, and of another who is donating for stem cell research. Further, it opens doors for egg trafficking and egg tourism by allowing donation from women who are not citizens. (Doctors maintain that eggs are tissues, and not organs and, therefore, their trade does not amount to trafficking.) At present, women come into Israel as tourists and go to undisclosed locations for treatment.

In terms of research and informed consent, the Bill proposes that 49 per cent of the donated eggs can be used for stem cell research, ignoring the regulations with regard to human experimentation. There is no mention of the need for supervision and monitoring in the Bill.

Isha L'Isha is faced with a number of challenges in addressing the concerns with the Bill. For one, it is facing ideological isolation since no other women's organisation has joined it in this effort. There is a fear among women's organisations that raising this issue will be seen as working against women who are in need of donated eggs in order to have children. Further, there is a complete absence of the rights discourse and a reluctance to talk about it since discussions have been dominated by doctors.

An overriding contextual challenge also exists – one cannot come out in the open in Israel and say that all women may not want to have children!

However, in the last two years, Isha L'Isha has become an expert on this legislation, issuing an extensive research report that had high demand from policy makers and the public. It has been an integral part of all parliamentary meetings on the subject and has managed to involve many organisations and researchers, thus forwarding its feminist perspective on the issue into mainstream political discussions.

The next steps for Isha L'Isha include: following the political process of the Bill; investigating characteristics of local trafficking; action research on the different voices among egg donation 'actors'; raising public awareness about the connection between organ and egg trafficking; carrying out information campaigns about the procedures and the dilemmas of egg donation; engaging with religious parties.

### **Globalisation and Gametes: Reproductive Tourism, Islamic Bioethics and Middle Eastern Modernity**

#### ***Marcia Inhorn***

Reproductive tourism has been variously defined to reflect the traveling of people from one jurisdiction or country to another, to obtain the kind of reproductive help they desire. It is part of the larger phenomenon of medical tourism. There are several factors promoting reproductive tourism:

- The prohibition on the use of services in one country for religious or ethical reasons;
- The unavailability of expertise, equipment, or donor gametes in one region;
- The lack of a service because it is not considered sufficiently safe or because its risks are unknown;
- Certain categories of individuals may not receive a specific service on the basis of age, marital status, or sexual orientation;
- Services operate on a market or quasi-market basis, thus affecting affordability and supply;
- Services may be cheaper in other countries;
- Privacy concerns.

Globalisation can be defined briefly as the development of 'ever faster and ever

denser' networks and streams around the world. Globalisation theorists understand globalisation through lenses such as global 'scapes', assemblages, frictions and shadows. Arjun Appadurai categorises 'scapes' as ethnoscaples, technoscapes, financescapes, mediascapes and ideoscapes. Additional categories can be proposed which are of concern to medical anthropology and global health: bioscapes (pathogens, vectors), somatoscapes (gametes, organs, body parts), toxiscapes (pollutants, chemical substances), pharmascapes (medications, illegal drugs), foodscapes (junk foods, McDonald's), lifescapes (sedentarism, addictions) and now, *reproscapes* which are also linked to other scapes:

- Circulating reproductive technologies (technoscapes);
- Circulating reproductive actors (ethnoscapes);
- Circulating body parts (somatoscapes);
- Large-scale global IVF industry (financescapes);
- Images of making babies 'on holiday' (mediascapes);
- Ideas of test-tube babies (ideoscapes)

The ART industry is booming in the Middle East although it is not spoken about in the Islamic Sciences. There are new forms of ARTs which are being made available: ICSI, third-party gamete donation and surrogacy, multi-fetal pregnancy reduction, ooplasm transfer, cryopreservation of unused embryos, PGD, embryonic stem cell research, and human cloning.

The notion of 'local moral worlds' can be used to understand the commitments and stakes

that make up everyday experience. *Fatwas*<sup>4</sup> issued by different clerics represent the moral/religious-authoritative position on ART. In Sunni Islam, IVF is permitted provided the eggs and sperm used are the couple's, and the fertilised embryo is transferred back to the uterus of the wife. Third party donation of any kind (including surrogacy) is not allowed. IOMS (Islamic Organisation for Medical Sciences), in 1997 issued a landmark declaration that has put this ban in place in the Sunni world. Many Muslim countries prohibit sperm donation (1997 global survey). Since children from the same donor may meet and marry at some point, therefore, it amounts to adultery and incest. It confuses kinship, paternity, descent and inheritance. Since the preservation of the 'origin' of each child is considered a moral imperative, as such, third-party donation would destroy a child's lineage. It implies a 'mixture of relations' and that a 'stranger enters the family'. A child born out of donation is called *ibn haram* (son of sin) and *walad zina* (child of rape). Adoption in the Muslim world faces cultural and legal prohibitions. However, a few Sunni Muslim IVF patients are willing to go 'against religion' and adopt.

Shia Islam's highest religious authority, Sistani, too opposes donation for reproduction. Ayatollah Ali Khamanei, however, has issued a *fatwa* that allows the acceptance of donor gametes (both egg and sperm). Both the donor and infertile parents must abide by religious codes governing parenting and the donor child can only inherit from the donor. The infertile parents have the status of adoptive parents.

There are some points of disagreements between those following the *Ijtihad*<sup>5</sup> and those who abide by Shia prescriptions: whether

<sup>4</sup> A fatwa is an Islamic religious ruling, issued by a recognised religious authority in Islam. (<http://islam.about.com/od/law/g/fatwa.htm>)

<sup>5</sup> Ijtihad is a technical term of Islamic law that describes the process of making a legal decision by independent interpretation of legal sources, the Qur'an and the Sunnah (<http://www.answers.com/topic/ijtihad>).



third-party donation constitutes *zina*, or adultery (if there is no touch or gaze), whether the child follows the name of the infertile father or the sperm donor, whether donation is permissible if donors are anonymous, and whether the husband of an infertile woman needs to do a *mut'a marriage*<sup>6</sup>, or temporary marriage, with an egg donor and whether a married Shia woman can have a *mut'a marriage* with the sperm donor. In theory, only widowed or single women should accept donor sperm, but single motherhood of a donor child is socially unacceptable. Iran has recently made sperm donation illegal, but the route of temporary divorce continues to be used.

In practice, Shia gamete donation is occurring in Shia majority areas like Iran and Lebanon. It is considered a gesture of 'marriage saviour'; helping to avoid 'marital and psychological disputes'.

Where egg donation is taking place, the sources are other IVF patients, friends or relatives, anonymous donors, including American women who travel to Lebanon to anonymously donate eggs. The recipients are Shia Muslim couples (including from the Hezbollah<sup>7</sup>) and Sunni Muslims who are 'reproductive tourists'. Sunni reproductive tourism is conducted in the secrecy of a 'holiday', maintaining the anonymity and confidentiality of the 'tourists' as well as phenotypic similarity. Sunni Gulf Arabs are known to travel to Tehran.

The current Middle Eastern reproscape is thus characterised by: significant medical trans-nationalism and reproductive tourism, mixing of gametes across national, ethnic, racial and religious lines, birth of hundreds

of donor babies to devout Muslim couples, reconsideration of biological kinship and social parenthood, weakening of the Sunni Muslim ban on third-party donation, Shia gametes entering Sunni bodies, despite the supposed rift, and a Middle Eastern modernity, despite the purported 'medieval theocracies'.

In conclusion, the notion of modernity is central to the understanding of ARTs, wherein ARTs are held up, in countries like Iran and Lebanon, as proof of modernity. Despite its reputation as a backward medieval theocracy run by Ayatollahs, Iran is in fact charging ahead in fields like ARTs, donation, vasectomy, nuclear energy, surrogacy, transgender surgery, etc. ART clinics are thus, used as a signifier of modernity.

## Discussion Points

- Nationalism may be a part of the picture with ARTs in Israel, but it is not the only reason. Every citizen in Israel has the right to IVF, Jewish or Palestinian. In reality of course, there is differential access, for instance, there aren't enough IVF clinics in Palestinian areas. Jewish leaders would want more Jewish children even if they were in Eastern Europe. For egg donation from Eastern Europe, religious men accompany the couples and claim that the women who donate eggs do so because they really 'care' about the suffering of other women. This also involves a process of 'becoming Jewish'.
- As an organisation, Isha L'Isha does not choose the actors it works with, they are already there! Of course coalitions are problematic and have their limitations. We have to be very

<sup>6</sup> Mut'a marriage is a fixed term contractual marriage in Shia Islam (source: [http://en.wikipedia.org/wiki/Muta\\_marriage](http://en.wikipedia.org/wiki/Muta_marriage)).

<sup>7</sup> Hezbollah is a Shia Islamist political and paramilitary organisation based in Lebanon. Hezbollah is now a major provider of social services, and a significant force in Lebanese politics (source: <http://en.wikipedia.org/wiki/Hezbollah>)

careful when we work with rabbis. We have faced similar problems in the past – in a coalition against pornography that Isha L'Isha did not want to be a part of, because participating rabbis included kissing on TV, gay couples, etc. in their definition of pornography!

- Although religious leaders are also known to conveniently ask couples to have more children in the supposed interest of their religion or race, the relationship between religion and ARTs is complex. On the one hand, when religious leaders do not allow ARTs, it is considered a suppression of individual choice with a geneticisation outlook. On the other hand, when religious leaders allow ARTs, it is seen as a victory of commercial interests over strong religious and cultural norms. Therefore, we are treading a thin line with religion, and the motivation behind allowing ARTs – whether it is a 'liberal' outlook or commercialisation – is not clear. In their desperation and desire for a child, couples have been known to agree to gamete donation and artificial insemination despite religious prohibitions and laws.
- In the Middle-Eastern world, states are powerful as police states, but in the bioethical world or the world of medicine, they are incredibly weak. In the wealthy parts of the Arab Gulf, there are so called 'angel investors' – sheikhs who may be interested in infertility and become patrons for clinics, which they fund. States don't regulate or legislate, and what is evident is a rather remarkable power of religion. Since the 1980s, the ban on third party reproduction has held. The few people who did bypass this ban, did so by going out of the country. We are definitely walking a thin line of judgment on religion. As feminists, our knee-jerk

reaction to these technologies is negative. However, the documented experiences of hundreds of infertile couples, who desire children for the joy of having a baby, point to the need to examine the implications of the restrictions imposed by, for instance, Egypt not allowing gamete donation and forcing women to travel to Beirut. Should we at all use value-loaded words like conservative, liberal, progressive, traditional? Not all of ARTs are 'bad' and not all of it is undesirable; it needs more control.

- The state is intervening in Egypt by trying to provide these services for the poor through state subsidized clinics, given that only the rich and the middle class have access to what is being seen as a 'reproductive right'. Israel has the most generous subsidies in the world. This is another feminist question: is it a reproductive right for the poor to have access to ARTs? Infertility in Sub-Saharan Africa is amongst the highest in the world, and women from there have articulated their demand for this technology that people everywhere else in the world are accessing. In such circumstances, it is very hard to say whose agency, freedom and rights are being denied.
- In general, there are no laws relating to ARTs in the Middle East. The United Arab Emirates is working towards the first law on ARTs in the region, which has been passed. However, religious law is what is influencing the reproscape in the Middle East. Feminist groups have not taken up ARTs as an issue, and have focused on other issues like female genital cutting, honour killings and so on.
- Mut'a marriages are stigmatised, and were invoked after the Iran-Iraq war when there were many male deaths, as a way for

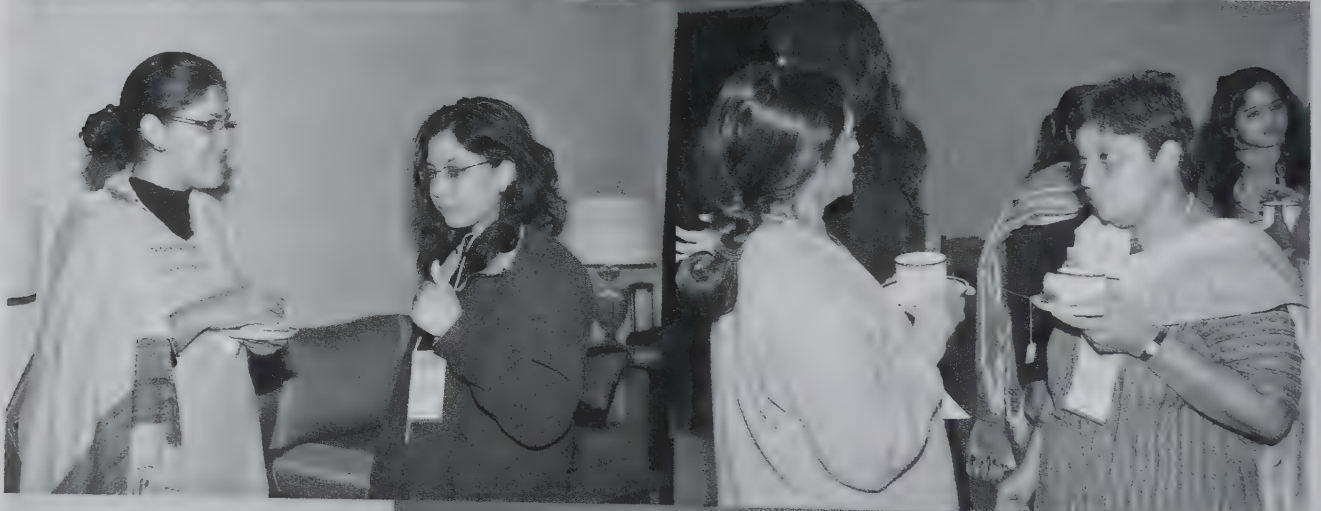


widows to get support through temporary marriages. This has morphed into a sort of prostitution now, though ART clinics are now invoking it. There are mixed responses to whether Mut'a marriages are necessary for gamete donation to be acceptable.

- While Lebanon has had many war orphans, long term guardianship prevails and orphanages are run by Shia charities because of the prevention of legal adoption. Therefore, people do give money, but the idea of raising an orphan in your home is very uncommon and is not considered a good option by the Shias as well as the Sunnis. This further complicates the problem of infertility. While adopting orphans is not a problem in Israel, there is a larger problem of adoption because there aren't many infants to adopt.
- Women are not at the centre of IVF in Israel. The doctors in their 'generosity' don't even wait one year to begin infertility treatment. This is medicalisation of women's bodies, motivated by the money in this business. Most women's organisations in Israel do not want to take up the issue of the Bill, because it is becoming a scenario where women are up against other women. Moreover other problems like the occupation, economy, etc. are on their agenda. Further, Israel is not a 'third world country', so no foundation is willing to fund work on these issues. Perhaps the money will come

in once the trafficking of eggs becomes as big a problem as the trafficking of women!

- In the Israeli Bill, the percentage of eggs that go into research is probably 'only' 49%, because they didn't want to be greedy! This bill has tried to connect the so called 'needs' of research and of women. After much discussion, it was reduced to 20% or 2 eggs, whichever is lesser. Further, while the Israeli legislation allows lesbian couples to use their eggs and have babies, it does not help gay men. Gay Israeli couples are buying eggs from Israeli or American women and coming to India for surrogacy through agencies. This has been documented in the film Google Baby.
- The focus of Isha L'Isha's campaign is to give information. Women can not be told not to donate eggs because it is risky twenty years from now. They have to be given material to think about; not just about the procedure and the side effects, but also on questions like – how do we feel about some children around the world not knowing about their parents; what if you cannot have a child later (for whatever reason) and you know there may be children from your egg donation somewhere; how about not being 'anonymous' and instead being a 'new' kind of family?
- One way to limit trafficking would be through laws in our different countries against fertility tourism.







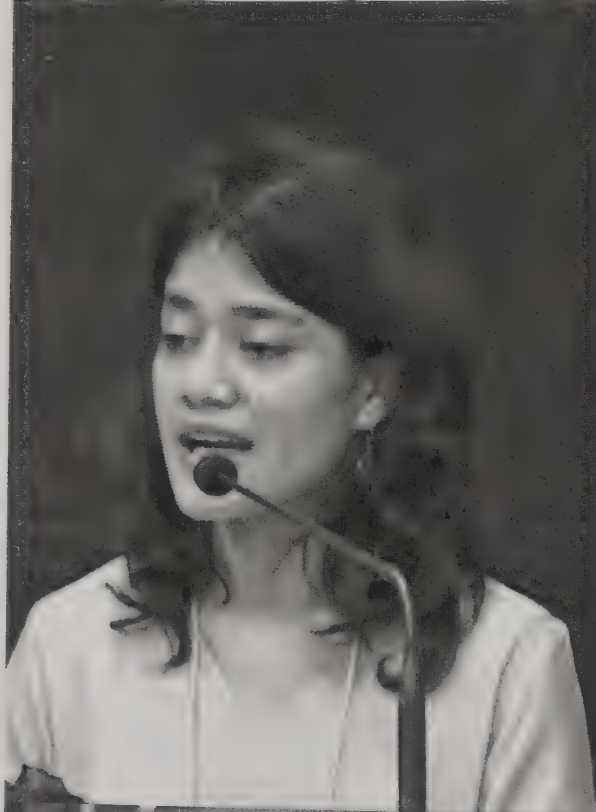
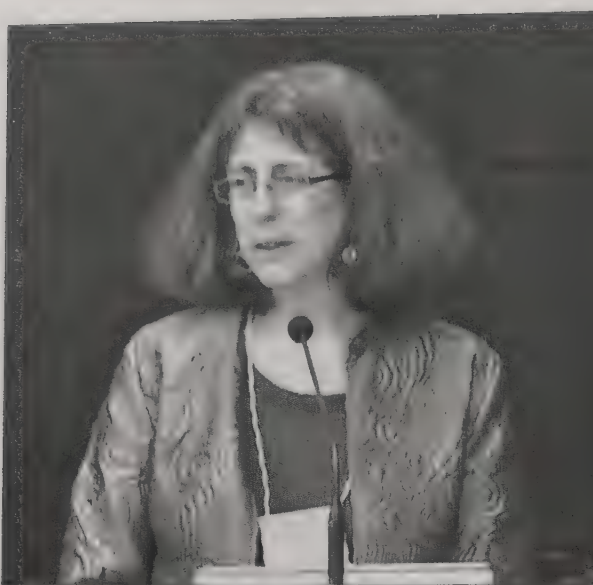






# Sama - Resource Group for Women and Health







# Global Experiences: US, Canada and the Netherlands

Coordinators: Amar Jesani and Sarah Hodges

## **Commercialisation of Reproductive and Genetic Technologies: What Lessons for Biotech Developments around the Globe?**

*Marcy Darnovsky*

The US fertility industry is a lucrative and ever-expanding business, operating with very little by way of public regulation or oversight. While most of the programmes are concentrated in the private sector, few are also operated by public universities. The industry has become highly competitive, with estimated yearly revenues of US \$ 3-5 billion from more than 400 ART programmes, seeking to attract customers who often have no insurance coverage and pay for fertility treatments out-of-pocket.

Some fertility firms are now merging, or opening branches in multiple cities. There is a search for new marketing strategies like money-back guarantees, discounts and special offers – prospective customers being lured to an information session by offering a lottery for free donor eggs, etc. New market niches are also being sought out, including people who are not infertile in any medical sense, but who might be willing to pay for procedures like sperm sorting for sex selection, and egg freezing as a backup plan for women who want to postpone childbearing.

The term 'reproductive tourism' generally conjures images of North Americans and

Europeans going to Eastern Europe or India where costs are lower. But the US is also a destination, with people with enough money coming in to avoid regulations in their own countries. In fact, the US has cornered the global market on so-called 'high end' eggs because unlike many other countries, there are no limits on compensation to young women who provide their eggs. In campus newspapers, advertisements seeking eggs for enormous amounts of money (\$20-100,000) are routine. Since the onset of the financial and economic crisis, there has been a surge in the number of women applying to sell their eggs or serve as surrogates.

Assisted reproduction is a political hot potato in the US, in large part because of the continuing and deeply partisan struggle over abortion rights. As a result, there is little public policy that directly addresses ARTs, and the policies that exist in different states vary widely.

The only federal law is the 1992 Fertility Clinic Success Rate and Certification Act. Beyond the CDC data, there are no federal mandates to report or to study the outcomes of ARTs for women or children; nor is there a federal law addressing PGD, sex selection, sale of gametes, surrogacy, reproductive cloning, or inheritable genetic modification.

Food and Drug Administration (FDA) regulates some of the drugs and devices used

in ARTs, but not ART practice per se. It is also mandated to look only at safety and efficacy, not at other social consequences.

The state regulation that exists is a patchwork of very divergent laws. Fourteen out of the 50 states have regulation of some sort about insurance coverage for fertility treatment. A few require that sperm and egg providers be medically screened or specify who has parental rights in the case of third-party involvements. A few address compensation for eggs or surrogacy, which also vary widely. Louisiana bans the sale of eggs. California law prohibits reimbursement beyond direct expenses for acquisition of eggs for SCNT (Somatic Cell Nuclear Transfer). Some states void surrogacy contracts and some states are known as surrogacy friendly.

There are now new battlegrounds because right wing forces have been introducing (in the states and at the federal level) bills to prohibit sex selective abortions. This is a bold attempt to co-opt some of the concerns that have been raised by feminist and women's health groups, and use it to chip away at abortion rights.

Courts have established a lot of the on-the-ground policy in the United States. The most common litigation related to ARTs arises out of disputes about the custody or disposition of stored embryos. There are also some high-profile surrogacy cases.

There are ethical guidelines issued by the practice and ethics committees of the industry organisation, American Society for Reproductive Medicine (ASRM). These focus on safety, efficacy and privacy for ART patients and address topics including advertising, informed consent, disposal of abandoned embryos, sex selection, payment levels for eggs and number of embryos transferred. Compliance is entirely voluntary, and many of the guidelines are widely and

openly violated, including those on social sex selection, compensation to third-party egg providers, and numbers of embryos transferred. According to CDC data, the recommendation for the number of embryos transferred is not followed by about 45% of the clinics, and in California, this figure is as high as 82%.

The concerns of CGS came not directly out of work in women's health, but out of recognition that an advocacy campaign was being run by a number of influential scientists in favour of Inheritable Genetic Modification (IGM) and a new market based eugenics in the late 1990s and early 2000s. A key event was a conference held at UCLA (University of California at Los Angeles), called Engineering the Human Germ Line, organised by Nobel scientists among others, who described this event as their effort to win the acceptance of the American public for a new eugenic vision. CGS emerged in the context of a civil society deficit in the face of the techno-utopian vision of 'designer babies' through reproductive and genetic technologies.

From the beginning of its work, CGS saw that these issues are necessarily global ones and that there will have to be international organising and agreements on a few fundamentals like prohibition of the most socially dangerous applications of reproductive and genetic technologies, especially IGM and also reproductive cloning. For some audiences at least, it is very powerful to point out that there is an emerging 'international consensus against repro cloning and IGM', that these applications have been prohibited by around four dozen countries and are addressed in Europe under the rubric of human rights and that there is strong sentiment internationally against social sex selection, the use of embryo screening for cosmetic traits, and an unrestricted market in eggs and wombs.



Some of the work CGS has done has been with women's health and reproductive rights groups. It was clear from the start that these technologies were already putting special burdens on women, and that reproductive rights and women's health groups would be key constituencies in our work, along with disability rights, LGBT and racial justice groups.

Unfortunately, reproductive rights organisations in the US have not been natural allies in these efforts. The ongoing attacks on abortion rights, especially during the Bush presidency, has pushed many mainstream feminists further into what is called the 'choice trap' – the libertarian position in which individual autonomy trumps social justice or the common good, for which there doesn't seem to be a counter political vocabulary. In 2002, the Planned Parenthood Federation of America (one of the largest national reproductive rights groups and abortion providers) came very close to taking an official organisational position in support of reproductive cloning as an extension of women's right to choose. In a strategy to tackle the frosty reception from reproductive rights groups, together with *Our Bodies Ourselves* (OBOS) and the Committee on Women, Population and the Environment – some of the few feminist organisations to take these issues on in a critical way – a meeting titled 'Gender and Justice in the Gene Age' was organised in the spring of 2004. Of the 65 people who were invited, many were from women of colour organisations developing a 'reproductive justice' framework that was meant to address some of the other shortcomings of the choice approach. This turned out to be a landmark

meeting. One result was that CGS was able to secure funding to begin a programme on Gender and Justice that focused intensively on outreach to reproductive rights and justice groups, LGBTQ, disability rights groups and racial justice organisations – through workshops, briefings, round table discussions.

In 2007, the Gender and Justice Program became an independent organisation called Generations Ahead, whose initial aim was to put together a cross-constituency coalition focused on reproductive and genetic technologies. Unfortunately, due to deep funding cuts, they have had to cut back those plans and are focusing this year on sex selective abortions in the US.

As a direct outcome of the meeting, a handful of the participants began to focus on a measure on the November 2004 California ballot, the California stem cell initiative<sup>8</sup> that allocated US \$ 3 billion of public money to embryonic stem cell research and research cloning based stem cell research. The CGS, along with a few other organisations like the California Nurses Association (labour organisation with about 75,000 members), opposed the initiative, even though at the time, embryonic stem cell research had become a cause célèbre among American liberals and progressives. It was a difficult position to be in, and the measure was sure to win; with its promises of cures by Christmas and the US \$ 35 million spent on its campaign and so on. But support for the measure fell from 70 per cent to 59 per cent, at least in part, because of our efforts. Through this, we formed a small but important group called the Pro-Choice Alliance (PCA) against

<sup>8</sup> This measure established the California Institute for Regenerative Medicine to disperse the funds, set up a governing board dominated by the biotech industry and the research institutes that would be the recipients of public money, and exempted the agency from state laws requiring open meetings and limiting conflicts of interest. In fact, the text of the measure included the provision that its 'activities shall be exempt from any current and future state laws'. The one limitation the measure did contain was a prohibition on payments for eggs for research that was there in the law – a provision that the authors of the measure soon regretted, and some researchers tried repeatedly to undo.

Proposition 71, to show that there was a pro-choice voice that was critical of this enterprise, not because of opposition to embryonic stem cell research, but because this was poor use of public money, given other health care and research priorities, and the risk to women of egg extraction for cloning-based research.

In the course of its work, the Pro-Choice Alliance confronted strategic dilemmas that continue to exist. For one, do you work with the right-wing? The main voice against embryonic stem cell research was the Catholic Church and other right wing religious organisations, which reached out and wanted to work together. Although we decided not to, there were a couple of people in the pro-choice alliance who felt that they were more willing to bracket the question of abortion rights and work with right wing groups. Further, once the stem cell agency is established, there is the question of whether we should put pressure (through meetings, letters) to reform some of their policies and mitigate some of the bigger problems in the bill. The majority of the people in the Pro-Choice Alliance, including the CGS, decided to do that, and we have had some successes. Some other women in the alliance felt this was a mistake that it was legitimising an illegitimate institution. Therefore, they formed Hands Off Our Ovaries and worked with college students. Now in fact, we are coming together again to work.

To be clear about not working with anti-abortion groups does not solve all problems about who to work with. The question of just how big a tent do we need has been an ongoing one. Similar to the situation described in Israel, we are also often accused of being anti-science and anti-progress! In the United States, it is important to bring the message to progressives that the kind of neo-liberal and libertarian temptations faced today need to be resisted, and commitments to social

justice, equality and the common good must be recalled.

At this point, CGS is focusing on an annual meeting of people who are concerned about these technologies. This was a decision that came out of a series of strategy meetings held in 2008 in 6 cities, and out of the realisation that there are many people in the country working on overlapping concerns with regard to these technologies who don't even know each other. We have been fortunate enough to get a minimal funding commitment to hold an annual meeting for the next three years, starting July, in Tarrytown, New York. The Tarrytown Meetings will bring together scholars, civil society leaders, policy experts and others to try and find a way forward. We hope to emulate what this meeting is doing in terms of bringing rich detail to the on-the-ground activity, in the context of larger theoretical and political issues.

### **Closing the Barn Door after the Horse has Bolted: Canadian Experience with Regulating Assisted Human Reproduction**

#### ***Shree Mulay***

Canada has the distinction of many firsts. First, it has the largest coalition of women's organisations (over 500) to have lobbied for new reproductive technologies' legislation. The coalition includes trade unions, women's committees, women's shelter workers, feminist community-based organisations and women's studies groups. Secondly, this led to the establishment of the most expensive Royal Commission (\$29 million) on the study of New Reproductive Technologies (NRTs). Thirdly, it has the distinction of being the country that took the longest time from the creation of a report to passage of legislation.



The NAC (National Action Committee)<sup>9</sup>, along with many groups have consistently raised the question of why the government was permitting the proliferation of IVF clinics without conducting a larger debate on the social, moral, ethical, and health impact of these technologies on society. The conservative government's response was to set up a Royal Commission on New Reproductive Technologies (NRTs) to receive 'advice'. The lengthy process meant that IVF clinics could carry on business as usual and introduce procedures quickly so that they were well established.

Social movements like the NAC have had to face many challenges:

- They had to mobilise and do consciousness-raising at the grassroots level and at the same time interact with political power structures to influence policy-making.
- In the area of NRTs, the NAC delegated responsibility to feminist 'experts' to develop policy recommendations. They, nevertheless, did not have full consultations. Very often grassroots organisations were left out and their opinions not considered.
- Furthermore, NRTs were not the only issue on the table. Access to abortion, childcare, minimum wages, and violence against women were also issues to be tackled. Diversity and representation of immigrants, and women of colour also occupied the internal political debates, which at times were very contentious.
- Work by volunteer boards meant that there was not sufficient time to develop a consensus on all aspects of NRTs.
- The Royal Commission fired two feminist commissioners because of their

outspokenness. This was the only inside track that the advocacy groups had that was also lost when these two women were fired.

Nonetheless, research into the use of technologies ranging from ultrasound to IVF and ICSI were examined and a final report of 1,275 pages, and two-volumes with 293 recommendations was submitted. The report entitled '*Proceed with care*' banned some procedures altogether, like making of inter-species chimeras, germ line modification, sex selection for non-medical purposes, payment for gametes, etc. It proposed regulating other areas – criteria for clinic license, number of eggs to be implanted, etc.

The report gathered dust until the Liberal government came to power in 1995 and the health minister introduced a Bill. This Bill had many flaws and was opposed by the right wing as well as progressive groups albeit for different reasons. The Bill died on the order paper when the parliament was dissolved.

A second Bill was introduced with many revisions prepared in consultation with the advisory committee, but women's groups were completely shut out with possibly one or two feminists on the advisory board who were in a minority. Ten years after the Royal Commission report, the Bill was finally passed in 2003 and became an Act in 2004. By this time the Conservatives were back in power, this time led by Stephen Harper, who was not only fiscally conservative but also socially right-wing. The board of the agency Assisted Human Reproduction Agency of Canada (AHRAC) was hand-picked to make sure that no one had connections with the grassroots movement.

<sup>9</sup> The National Action Committee on the Status of Women is a Canadian feminist organisation.

#### Current scenario:

- In the intervening years from the Royal Commission report to now (1993-2009) ARTs have proliferated and some things are being revisited (chimeras, for instance).
- The AHRAC jurisdiction has been challenged in two provinces. In Quebec, the French national identity has been asserted to say that health is a provincial matter and the federal government has no right to decide what services will be offered and how it will be paid for. In Ontario, Prof Amir Attaran has filed a human rights case stating that the AHRAC regulations discriminate because treatment is not covered by public health care. We expect more challenges to follow. The conservative government would be only too happy to use these challenges as an excuse to scrap the agency if it can.
- In terms of public health initiatives on infertility in Canada, nothing is being done!

#### Suggestions:

- Since reproductive services are offered across national borders, it is not sufficient to have a strong national regulatory framework. Rather, there is a need to harmonise and regulate the trade in Cross Border Reproductive Services (CBRS) for the protection of the users to ensure that the domestic health care system is not over-stretched as a result of use of CBRS. Consumer protection laws for CBRS and other health-related services are needed at the international level. In this context, international agreements on CBRS as a part of GATS are worth exploring.

- The widespread marketing of very costly reproductive technologies and the burning desire to be birth parents drives couples to take risks which they would hesitate to take in other matters. However, 'caveat emptor' (buyer beware) underscores the need for reliable information about services and this needs to be made available in an easily understandable way.
- Some countries have moved forward on storage and disposal of frozen embryos and the circumstances under which they may be used for stem-cell research, but a large majority of countries – the net exporters of CBRS – do not have clear guidelines on these matters. These need to be addressed internationally.
- A matter of considerable concern is the trafficking in oocytes and embryos for IVF and research purposes. An international legal framework is needed to regulate and to ensure that women are not exploited as a source of oocytes and embryos.

#### Areas for further study and research:

- The ICMART (International Committee for Monitoring Assisted Reproductive Technologies) has reported on the number of IVF cycles and live births from data collected from 49 countries. However, there needs to be specific monitoring of ART services in general, and the outcome of multiple and ICSI pregnancies.
- Evaluation of IVF procedures, their appropriateness and their psychosocial impact on women serving as surrogates.
- Cultural aspects of delivery of IVF and surrogacy services need to be studied to develop a better understanding of their long-term impact on society.
- If we want to work for a paradigm shift in ARTs, we have to: assess our successes and failures in campaigns to eliminate and



reduce harm from unsafe contraceptives; use what we learn to develop a campaign that can reach a wide range of women in newer forms (social networks, blogs, websites), in addition to materials for women who do not have access to these, especially for rural women; decide on how we will interact with the state. It is not a uniform monolithic with a well-formed legislation agenda in any area. They, whosoever 'they' may be, are first and foremost subject to social forces and pressures.

Although feminists have had an uneasy relationship with the state, yet the baby steps that have been taken – whether they are in the field of equity in wages, recognition of violence against women and laws to prevent this, gun control – have happened with effective lobbying at federal and provincial levels.

## **Bio-crossings and the Global Fertility Market**

*Jyotsna Agnihotri Gupta*

Some of the striking features of the fertility sector are the entrenchment of technology, premium on the concept of motherhood, viewing women as co-producers, and absence of self-regulation by the industry or by other agencies. A new vocabulary is emerging around fertility services – 'Thinking of having a baby?', 'Finding it difficult to get pregnant?', 'Want to know how fertile you are?', 'Considering IVF?' 'Looking for some answers?'

A Fertility Show was organised in London in November 2009, of which, the Infertility Network in the USA was a co-organiser. There were 300 stands at the show offering IVF holidays, sending people to other European countries. It was the first ever trade exhibition

for 'making babies' and business was brisk. Its promotion tagline was: 'Sometimes nature needs a helping hand; give yourself the best chance.'

There were a range of service providers and businesses that had set up shop at the Fertility Show, like *Chelsea & Westminster Assisted Conception Unit*, a business that calls itself 'Fertility Astrology' and claims to be able to assess the quality of your eggs by mapping your stars and *Innermost Secrets* that encourages younger women to check their fertility levels before it is too late.

A concept that needs examination in the current scenario of the fertility market is of 'biocrossing'. A term coined by Aditya Bharadwaj, it is defined as 'a crossing' between biology and machine, and across geo-political, commercial, ethical and moral borders. Assisting conception has become a thriving business globally and includes crossing national borders. Clinics in Southern European countries such as Spain, Crete, Cyprus, offer 'IVF holidays' to relatively wealthy North European couples seeking assisted reproduction services, who have not been able to obtain the treatment in their home countries, either due to legal or financial barriers or long waiting periods. Fertility clinics in the Ukraine and other countries of the former Soviet Union recruit young East European women and send them to clinics in Spain and other locations, like Cyprus and Belize, to provide oocytes for North European couples.

There are many facilitating factors for this cross-border trade: opening up of the European Union, making trade and travel within states easier; differences in regulation between countries; easier access to information through the Internet; neo-liberal market ideologies. Cross border trade arrangement

could include the recipient visiting the donor's country, or the donor visiting the recipient's, the transport of gametes and embryos, or medical doctors and researchers visiting the source of supply of oocytes and the site of financial and regulatory support.

Of the 20,000-25,000 Europeans who travel abroad for fertility treatments each year, 3,000-3,500 are from the Netherlands. Of the 43,000 children born every year in the country, 25 per cent are born to women over 35 years of age. In 2003, around 7,000 women in the age-group of 40 to 44 years gave birth to their first child. Individuals or couples have to bring their own donors who they must find within their own family, friends, or ask if someone is willing to be a donor through putting up a call on dedicated websites. Egg donation, however, is rare and accounts for no more than 100 pregnancies per year.

The legal norms governing the country do not allow commercial sperm, egg/embryo donation or surrogacy. Egg donation and surrogacy are permitted only with people one knows (family or friend may act as a surrogate). With the promulgation of the law dealing with registration of egg, embryo and sperm donors within artificial conception, anonymous donation is no more possible. Every donor is registered and every child born through this procedure can have access to the donors' data. The data are maintained by the Foundation for Donor Data Artificial Conception, a national registry of all data regarding egg, embryo and sperm donors. In the case of a child born through sperm donation, she/he has the right to seek information about the donor at the age of 16 years.

The maximum age for accessing IVF is 45 years. There is a demand from the medical community to increase it to 50 years. Lesbian couples and single women are also eligible to access the services. Also, advances in the technology of cryopreservation of eggs raise new hopes for women above 40 years.

There are 13 IVF labs in the Netherlands. In some regional hospitals, certain procedures (barring IVF) related to infertility treatment are available (blood tests, ultrasound, HIV and hepatitis tests). Every year about 1,500 embryos are left over after infertility treatment. The choice is to cryopreserve them, donate them for research or destroy them. Most choose the last option. A maximum of two (often only one) embryo may be transferred to prevent complications associated with multiple pregnancies for mother and child(ren).

You can choose between English, Danish and Lithuanian language options are available on the website of the Danish fertility company, *Nordica*, which offers oocytes through a Spanish clinic. Their website states – 'we have a cooperation with a fertility clinic in Spain. The clinic has a great experience with egg donation and also offers eggs to women with a Scandinavian look. If you want egg donation abroad, all consultations, preliminary examinations and the medical treatment take place in the Nordica Fertility Clinic. The fertilisation of the egg and the transfer of the fertilised egg take place in Spain. After your homecoming, the after-treatment takes place at Nordica'. In all, there are 10 Nordica Fertility Centres worldwide. These centres are part of an even larger network of fertility specialists working together with Nordica.

The overriding issue in accessing fertility services is that of commodification versus self-determination.

## Coordinators' Comments

### *Sarah Hodges*

While we consider strategies that have worked in the past, particularly the critical engagement with population control and campaigns for safe contraceptives, we also



need to ask if the same strategies will work here, given the difference in context today. Reproductive technologies are part of a new neo-liberal world that seeks not to contain people (in borders and populations) but seeks instead, new markets and new material to commoditise.

## Discussion Points

- Generations Ahead will focus their work this year on sex selective abortions. They will do 3 things firstly, they will work with South Asian women's groups since the latest US census shows that amongst certain Asian populations in the US, there is now a discernible sex ratio difference because of son preference. Secondly, they will also work with fertility professionals who are disturbed with the growing sex selection in the US. Thirdly, they will work with reproductive rights groups on opposing the bills that have been put forward against sex selective abortions. The hope, as a defensive strategy, is that the reproductive rights groups that will oppose the sex selective abortion bans will oppose them because they are against the attempt to undermine abortion rights, without appearing to support sex selection.
- The 'choice trap' is a 'libertarian temptation' that has been strong for a lot of elements on the American Left, and for reproductive rights organisations in particular. It started as a tactical strategy to struggle for abortion rights in terms of privacy and choice. Privacy was a legal strategy in the Supreme Court because of how the US constitution is structured. However this, together with other political and cultural dynamics, has worked to push reproductive rights advocates into an unfortunate position, where we talk about individual liberties but not about the social vision of gender equality. However, there is a lack of political vocabulary, even on the American Left, to address questions of ethics and morals, as well as common good and solidarity.
- Apart from the Convention on Biological Diversity and TRIPS, there are two other agreements – GATS and WIPO (World Intellectual Property Organisation) – that need to be engaged with and critiqued, especially since they regulate between states. An overarching convention is required that can bring in the perspectives of human rights, women's rights, CEDAW (Convention on the Elimination of all forms of Discrimination Against Women), etc. There is a need to connect international agreements with futures and the betting on the products of spare embryos. These rely on the disentangling of women's bodies and moving its parts away to a profitable space.
- Is religion bowing down to the call of the market? Religion is always invoked as a factor in conversations about the Middle East and South Asia. We also need to discuss religious groups in America and Europe that have been active on abortion and stem cell issues, as well as church organisations that are progressive on the environment and other issues, including the Pope. Efforts have been made in the US by groups like the National Council of Churches and more liberal churches like the Methodists.
- An important strategy could be a research project that looks at the way in which financial systems, based on certain definitions of property and risk, connect with the biotech and reprotch industries. We need to develop a strategy vis-à-vis not just the state, but also big corporates and their functioning.

- We need to reflect about strategies from the population control and contraceptive campaigns; we have not as yet succeeded, as population control continues to take place in other forms. Though it was the feminist movement that was addressing issues within population control, all discourses (from official articles to student dissertations) on reproductive health and rights begin from the ICPD (International Conference on Population and Development). Globally, public memory of feminist voices has completely vanished. Feminist strategies have always been against the state and hence, very low key.

Given the amount of cross-border movement today, which campaigns do we locate at the local level and which at the global level? We need to say that women's reproductive material cannot be property under GATS or TRIPS, or the latest insertion into a chain of commodities – high yielding varieties of seeds, cattle and now, women's wombs. A different articulation of women's reproductive rights and sexual health issues is needed. Further, we need to engage with the problems in the language of altruism, gift-giving, donations and ask questions that are difficult even for feminists. If surrogacy

is okay, why is sex work not okay? With the same body, women are either having children without sex (in the case of surrogacy) or are having sex without children (in the case of sex work). Why should one have a higher value, while the other is criminalised? Further, if we put all these issues under the umbrella of exploitation, what do we stand to gain and lose? We need to have a clear understanding of our bodies, in a way that goes beyond compartmentalised and patriarchal ideas about our bodies, even as feminists.

- We need a series of maps – a map of bio-crossings that shows the global flow of business, surrogacy, gametes; a map of finance, from high level down to street level; a map of international regulatory agencies and a map of strategies from movements in different countries – laid out in a transparent way for activists to use.
- Perhaps, there is something to be learnt from the promotion of breast feeding in the fight against the baby foods industry. The promotion appealed to mothers because of evidence of linked malnutrition deaths.
- What are the legal cases that have been registered against the ART industry?



# Emerging Perspectives and Challenges

Coordinators: Renu Khanna and Young-Gyung Paik

## Renu Khanna

We need to assess our work with ARTs on the following counts:

- What are the challenges to movement building?
- How do we build a coalition within women's groups with different perspectives?
- How do we introduce the ART agenda into other social movements?
- How do we avoid co-option?
- What is the common minimum agenda that we should set for ourselves?
- What media products are we going to bring out and how will we disseminate them in alternative information spaces?
- How do we talk to the various stakeholders and use them at the strategy level? In order to get credible sources of information, we also need to build allies within other circles, like gynaecologists.
- Where is the demand for ART situated?
- We need to learn from earlier experiences while deciding whether ban or regulation is the answer.
- How can regulatory bodies be made transparent and accountable?

## Young-Gyung Paik

### Challenges

- We have to understand the components of the term *Assisted Reproductive Technology*. Is reproductive technology really 'assisted'?
- There is a need to map and keep track of what is going on in ARTs and its speed of development and expansion, in terms of regions, nations, forms and class.
- In assessing the demand for ARTs, it is important to interrogate the concept of 'family' and 'patriarchy' and the conflict of 'rights' within.
- There is an issue with too much information about some areas of ARTs (aggressive advertising and marketing) and too little information about other areas (risks, causes of infertility, statistics and clinical data). There is a lot of false information going around, even from medical authorities.
- Citizenship remains an unresolved issue in the case of surrogacy.
- Regulation and legislation of practices are potential sites for intervention.
- The concern with the lack of primary health care is paramount.

- Should we be looking for analogies when we try to determine our strategy and with what? Sex work? Organ donation? Blood donation? Tissue donation?
- How can we achieve and maintain solidarity in the area of reproductive technology?

### Strategies

- Rename the term 'ART' in a way that it can empower us and question concepts of 'altruism' and 'donation'.
- Create interactive maps of actors, movements and regulations.
- Production and dissemination of knowledge through action research, outreach and other means.
- Engaging with the law through legislation, lobbying, consultation, review and challenging of the existing or proposed regulations, and bringing cases to court.
- Connecting with other issues (environmental, political, economic, financial, intellectual property) and other movements (within the country and across nations).
- Identifying the different levels of action: local, regional and beyond.

### Non-negotiables

- Feminist perspectives and initiatives.
- Social, economic and environment justice.
- Community-based action, empowering the groups whose rights are not automatically acknowledged in the existing discussion; those who are not married, political and ethnic minority

groups, LGBT, disability groups, patient groups, etc.

- Strengthening primary health care and meeting basic needs.
- Making 'low-tech' options available.
- Expanding the public sector.

### Discussion Points

- There has to be clarity on the standpoint on *technology*: is the group against technology altogether and thinks it is problematic? Is it against assisted reproductive technology only and thinks that is problematic? Or is it against the way in which assisted reproductive technology is organised? The job of technology providers must be restricted to the provision of the technology and should not spill over into decision-making regarding who can access this technology or the citizenship status of the child.
- *Strategies* are required for the short and long term. In the short-term there has to be 'gap-filling' to stop the practice temporarily, and in the long term a whole paradigm shift is desirable. This can be under the broad and comprehensive umbrella of opposing medicalisation of women's bodies. However, in the effort to build strategy, a point of immobilisation must not be reached where infertility treatment becomes inaccessible for even those women who need and seek it. A possible research area that can feed into strategy is that of documenting the narratives of women who have accessed ARTs in different countries. In addition, different legal frameworks across countries need to be mapped. Alliances have to be built with people from other disciplines, including ARTs, who want regulation. A



list of non-negotiables should inform the strategies and goals. Some fundamental definitions like sex selection need to be revisited. However, there cannot be one universal strategy to address issues within ARTs because of contextual differences. The temptation to generalise has to be avoided because of the diversity in ART experiences and characteristics across the world. Representatives from each country have to volunteer to identify the problems in their own countries.

- The relationship between ARTs and the *neo-liberal economy* needs to be understood for better strategic alliances. It is important to examine what TRIPS and GATS are saying on ARTs and stem cell research since there are some peculiarities there.
- Currently, *heteronormativity*, the traditional family structure and the institution of marriage restrict some people from accessing these technologies. Possibilities of local subversions of these restrictions must be accommodated in our strategies.
- A large incidence of infertility is preventable and needs to be addressed.
- When drawing from the experience of population control, it must be remembered that population control was

imposed largely on poor and vulnerable women by a strong state. In the case of ARTs, the state seems to be a bystander as well as the site of some degree of moral discussion. Further, two public hospitals are offering fertility services in Delhi. Is our stand on public sector provision of ARTs the same as our stand on private sector provision of ARTs?

- Children born through IVF suffer harmful effects that are going un/under-investigated. Women, too, do not know the effects of IVF on their health.
- The perceptions of the Muslim community in India too need to be researched, considering it forms a large part of the Muslim world.
- A central message for awareness-raising campaign has to be developed (like 'Smoking Kills' in the case of smoking)?
- One of the differences among feminists with respect to women who access ARTs is whether to view them as victims or agents. How do we critically engage with women's choices? The differences of opinion among the participants at the consultation have to be recognised and understood – for instance, between regulation and banning, within regulation, and on the nature of regulation.

# Global Experiences: Latin America

Coordinators: Renate Klein and Marcia Inhorn

## **Egg Traffic in Ecuador in the Context of Latin American Reproductive Policy**

*Elizabeth Roberts*

There has been a definitive shift of health care in Latin America towards privatisation. Across the region, the public health sector has been completely devalued, with people who have few resources paying out of their pockets for expensive treatments in the private sector. However, at the same time there continues to exist a paradox within the region, with robust public health systems in countries like Brazil, Venezuela and Colombia.

Latin America is home to some active national and pan-national feminist organisations. Many groups working in these areas generally tend to look at reproductive and sexual rights as a package, and this is often reflected in their work. In terms of political activism and legislative debate, the arena of birth control is highly volatile and the morning-after pill has recently become one of the flashpoints of these debates. In Ecuador, for instance, different feminist groups were actively engaged in trying to legalise the pill, which resulted in a huge backlash because of which two varieties of the pill (thus far widely available without prescription, albeit illegally) were taken off the market and have now become unavailable.

Another issue that has been on the forefront of feminist activism in this region is that of sterilisation abuse. Although not as prevalent as it was in the previous decades, it still continues to remain an issue of major concern for groups working on reproductive rights and policy.

Abortion rights do not fall neatly in Latin America in terms of Left and Right wing politics. For instance, although the Ecuadorian president is leftist, he has had a very mixed record on reproductive rights and abortion policy. This has largely to do with the history of repressive regimes across Latin America in the seventies and eighties, and the support to the Left by the Catholic Church at that time, forcing them to lay down restrictive reproductive policies.

Over the years, there has been a simultaneous liberalisation and criminalisation of abortion law in Latin America. Until four years ago, Cuba was the only nation in the region where abortion was legal, with all the other nations having stringent laws against abortion. Interestingly, despite this, Latin America has the highest rates of abortion. Ironically, in Ecuador, safe abortion is available in the private sector, albeit illegally, for all those who can afford to pay for it. At the same time, the chances of unsafe abortions among poorer women who cannot afford these services are much higher, thus raising important questions



about the effectiveness and implementation of policies.

Recently, Mexico City made 'on demand' abortion legal, which was considered a huge victory by all the groups working on policy and reproductive rights there. However, as a huge backlash following this step, 10 states have adopted stricter abortion laws, criminalising the activity itself. Nicaragua and El Salvador have the strictest laws against abortion globally.

Many reproductive rights groups look at this phenomenon as a paradox. However, it is important to look at it simultaneously with regard to the rights discourse as well. On the one hand, there is the right to public health and the right to choose for the woman, and on the other hand, is the right to life and rights of the foetus that are often purported in this respect.

With these issues at the forefront of feminist activism, it is not surprising that ARTs have received very little attention from groups thus far. Barring a few groups in Brazil, none of the other feminist organisations have delved into the issue. Similarly, there has been no legislative effort to regulate ARTs in the region either.

From a religious standpoint, the Catholic Church is the only major world religious body that absolutely condemns all forms of ARTs. The condemnation of IVF relates to the fact that in the Church's view IVF is akin to abortion. Even though the couple going through the procedure may not destroy the embryos, the procedure is perceived as developed through the destruction of embryos. Moreover, there is the added objection of the processes not being 'natural'.

The effect of the Church doctrine varies across countries depending on the specific

relation between the Church and the state and the actual robustness of the state to effect change or implement policies. In Ecuador, for example, the Church has very little sway, while in Costa Rica it is obviously much stronger.

Mexico, Brazil, Argentina, Chile and Colombia - the nations with the largest economies in the region - not surprisingly, also have the largest thriving ART industries. There are absolutely no laws anywhere in the region that directly affect the industry. Or if they exist, they have not been relevant in any way. For instance, Article 20 of The Child and Adolescent Civil Code (2003) in Ecuador that states '*boys and girls and adolescents have the right to life from their conception... Experiments and medical and genetic manipulations are prohibited from the fertilisation of the egg until birth*', has been interpreted as - embryos should not be frozen. There have been several debates regarding this between IVF providers and policy makers, but it has not translated to anything, and any form of regulation remains completely absent. ARTs thus remain legal and largely unregulated in all the countries in this region, with only Costa Rica as an exception where IVF is banned.

All ART clinics are in the private sector where the practitioner or clinic has complete discretion over the practice, costs as well as the clientele of the clinic. Thus, issues such as whether the clinic will provide procedures for single women of surrogacy and egg donation, are decided by the practitioner. Some reproductive tourism also exists in the region, and movement from Costa Rica to Columbia is especially prominent. There are 12 private ART clinics in Ecuador (a nation of 12 million people); all of which, as in other countries, are completely unregulated and see a diversity of patients. In fact, in Ecuador, there is complete absence of regulation of private medicine of any sort, let alone ART clinics, except for a yearly sanitation inspection. Twenty five per

cent of the patients are generally resource poor, making around US \$ 300, in situations of massive debts, to pay US \$ 4000–5000 for an IVF cycle.

Another interesting observation has been that a lot of the poorer women at the clinic are there because of unsafe abortions in the past. Thus, they are becoming a classic example of being 'produced', in a way, for the IVF industry through the illegality of abortion in the country. It is important to consider this effect of abortion policies on other similar issues that effectively make consumers for private reproductive medicine.

Similarly, gamete donation in Latin America, like IVF, is rarely regulated and little attention is paid to donor health and other aspects. Certain professional organisations, like LA Red Latino Americana (registry for various clinics around the region), have developed certain guidelines in this respect but these remain non-binding. Many, but not all, IVF practitioners promote paid anonymous donors rather than known donors. However, at the same time, there are several instances of sisters, god-daughters, nieces or daughters (in case the mother remarries) donating their eggs. Moreover, even in the case of known donors, a financial motive is not always missing. Often younger women donate eggs to older women from whom they have had a lot of financial support in the past; this is a way of paying them back. It portrays a kind of financial interaction and exchange of kinship. Children born with the help of egg donation are considered to belong to the entire kin and not just to the couple. Since reproduction has always been understood to be 'assisted' (by god, family, etc.), ARTs are not seen as 'too far' from how children are generally produced. That is why, in a way, ARTs are much less problematic in Ecuador.

Practitioners in Ecuador are largely uncomfortable with surrogacy, and it is not generally advocated to the patients. Along with sisters and other female relatives, many a times the patients also recruit their domestic servants as surrogates.

Paid egg donors in Ecuador are typically students below 28 years, from the working class, non-virgins and light skinned. Race plays a very important role in gamete donation, with the long-standing history and virtue of '*mestizaje*' (*whitening*). Thus, doctors assume that patients want lighter skinned children, and lighter skinned women are sought for anonymous, paid donation. Many couples too prefer donors lighter than themselves and believe that using that donor will further contribute to the '*whitening*' of the nation. Racial analysis, therefore, is a component of egg donor profile. Unlike in the United States, they are very clear that they are doing it for money and do not give excuses of altruism. They donate eggs for money and receive US \$ 500 per retrieval, only if they deliver eggs. Many of the egg donors have also spoken about how going through the process of egg donation for them becomes a way to escape male control. It is often valued for this reason as it gives them the opportunity to participate in a high-class, privatised form of medicine. It is generally kept a secret and only shared with female relatives.

A summary of the assisted reproductive scenario in Ecuador, thus, points to: private medicine drawing patients across the class spectrum; known egg donation among kinswomen involving financial exchange; paid egg donors experiencing donation as an adventure and a way to participate in high-tech medicine; darker skinned women, who can be desirable IVF patients, not being considered desirable egg donors.



## Assisted Reproductive Technologies in Brazil: An Overview of the Scenario and its Ethical, Legal and Social Challenges

Marilena Correa

In the Brazilian context, the 'need' for a child is highly valued and it is considered unthinkable that a woman might want to live without a child. Along with the social medicalisation of contemporary societies, there is a medicalisation of childlessness as well. A recent research in a public hospital in Rio de Janeiro revealed that though infertility services are available, there is no high technology. These women are exposed to the idea of being treated, without being 'completely treated'. While the need and desire to set up a family is presented as an 'unfulfilled dream', there are also elements of embarrassment and stigmatisation that come with childlessness. This makes women vulnerable, and poor women particularly want access to these technologies – a small group of about 8 to 10 such women came together to claim access from the state. The vulnerability of women is also reinforced because of the irresponsibility of doctors who frame ARTs as a response to the 'need' for children.

ARTs were introduced in Brazil in the eighties and the first test-tube baby was born in 1984. ARTs were then almost only found in private clinics, but during the eighties, they organised a system of hands-on learning, by calling in and paying their foreign colleagues to teach them IVF. This was a *contradiction* because at that time Brazil also had good publicly-funded research programmes. Other innovations at the time did not enter the country in this way. ARTs have stayed in the private sector (where they came), and for public health, it is as if they do not exist.

There remains an inadequate monitoring of the results of ARTs, and a lack of registration

of its activities, either by the government or by medical societies. The Assisted Reproduction Latin American Network's registry too works on a voluntary basis, and they collect data only from clinics that want to give data. Therefore, the worst results do not show up. Only 50 clinics are present according to records, but actually there are more than 100. Though inconsistent, this is also the first path towards a monitoring mechanism. There is no control and a lack of political will from the public health authorities.

In the direction of regulation, the Federal Council of Medicine passed the first resolution in 1992. This is the main document regarding ARTs in Brazil, and is widely referred to by doctors. In the nineties, three bills were put up in the National Congress on Assisted Human Reproduction. The Ministry of Health called for a consultation on these bills and in 2005, the Brazilian Bio-technology Law was revised, which changed matters significantly. All efforts at regulation have been in the interest of the medical profession, and have aimed at legalising what medical professionals were already doing. While the consultation included people from diverse backgrounds, including feminists, what prevailed eventually was the view of the medical specialists. The resolution has permitted surrogacy and insemination for single women, but it does not talk about sexual orientation. Therefore, it does not have the 'universal eligibility' it claims to have, and in the private sector it is really a way to magnify the medical market. It is important here to note that in Brazil, it is a criminal offence to sell body parts, tissues and cells. The resolution repeats this, and talks additionally of informed consent.

When this bill was proposed, the doctors wanted to repeat the same chapters, articles and norms, but when it entered the national Congress, the bill suffered a more restrictive

bias. It was very 'liberal' and silent about many things. This has changed and now there are two bills up for voting, both with different points. One deals with surrogacy in the spirit of the resolution, and says it is possible to cryopreserve gametes and transfer up to four embryos. The other bill does not allow for these. The Catholic deputies and other religions like the New Protestants have actively exerted their influence to block laws. None of these bills address the need for monitoring and control, which goes to show the commercial interests that they are pandering to. The data collected by the *RED network* of centres of assisted reproduction in Latin-America does not take into consideration aspects like the effects of drugs, although their work does make available more information.

From cross-country data on IVF centres and data on ART procedures in Brazil over the years, it is evident that the number of embryo transfers and multiple pregnancies in Brazil are quite high, putting both women and children at risk.

Brazil faces many challenges in reproductive health including a declining fertility rate from 6.2 in 1960 to 1.8 in 2006. While the early period of declining fertility was caused by medicalisation through unsolicited pills and forced sterilisations, the more recent decline in fertility is associated with education. The population in 2009 was 192,343,632 of which 84 per cent was urban. The life expectancy is 72 years and the infant mortality rate is 22 per 1,000 live births.

The 1995 bio-technology law in Brazil forbade the genetic modification of plants, humans, seeds, etc. Genetic engineering could only be produced in a confined space for research. In 2004 the agro-business lobby, especially Monsanto, put a lot of pressure on the government. There was a huge public debate involving feminists, scientists,

environmentalists, firms, deputies and so on. The scientists were able to construct a discourse that projected the environmentalists as retrograde, and discredited the precaution principle. At the time of voting, agro-business and genetically modified crops had less support in Congress and in society; these firms had committed many illegalities. Brazil was the second largest exporter of soy and it was not clear to people why genetically modified soy would bring more wealth to the country. But the 'progressive' scientists aligned themselves to agro-business and mobilised patients and patients' associations, in the interest of 'curing disease', to approve human embryo stem cell research in the country. Now, the law in Brazil allows embryonic stem cell research, and these embryos come from IVF clinics where there is no regulation. In the last two years, a lot of regulations have come forth regarding aspects related to laboratory conditions but no questions regarding women have been featured. The doctors do not want to discuss these issues, and would rather perform IVF to earn money and 'fulfill dreams'.

Some unattended areas of regulation are: How many embryos should be cryopreserved? Where and who should keep them, and whose responsibility are they? What kinds of contracts govern such practices, as well as others, like egg donation?

The activities of the *RED network* include accreditation, logistical support, training and research. There is a need for more information on results, use of drugs, pregnancies, deliveries and newborns in Brazilian and Latin American clinics.

Some non-regulated and 'hidden' forms of commercialisation have been seen in Brazil, including egg sharing or donation in return for subsidising fertility treatment. One such example is Projeto Acesso.



Projeto Acesso (Access Project) sponsored by Merck-Serono since 2005, provides discounts for patients who present a condition defined as 'impaired conception'. The project also defines who its beneficiaries are – they cannot be completely poor because they have to purchase their drugs. Beneficiaries are said to 'have access' i.e. they can buy drugs cheaper and their ART medical fees are subsidised. Projeto Acesso operates in association with IVF clinics previously accredited by the firm itself. This practice is new and unregulated and paradoxical within Brazil's public health system, which functions on the two principles of universality and justice. There is also another system of private insurance for those who can afford it. However, 80 per cent of the population depends on the government, and the government does not want to introduce ARTs as they are too expensive, and infertility is not considered life threatening.

The practice of oocyte sharing and donation is present in the country at least since 1995. It is done in private clinics by doctors who recruit young patients with tubal problems due to abortions or untreated sexually transmitted infections. This practice is not paid, since the sale of human tissue is a criminal offence in Brazil. Overall, it can be concluded that there is an imbalance between this picture of privatisation and Brazil's public health system that takes care of all patients.

## **Coordinators' Comments**

### ***Marcia Inhorn***

- In trying to place the issue in a broader framework, intersectionality theory could be useful. Multiple interlocking forms of oppression – gender, race, class, religion – are not just additive but also multiplicative. We also need to place ARTs in the broader framework of women's reproductive lives and their health.

- We have unwanted pregnancies leading women to abortions on the one hand, and women who want children but are infertile on the other. One of our points of activism could be the emergence of ART as an end product of poor abortion, given that there are thousands of unsafe abortions in countries where it is criminalised. Unsafe practice of one kind is leading to a high degree of unsafe practice of another. This is a profound link, coupled with the fact that 'right to life' is probably the most important issue for the Catholic Church.
- From the high prevalence of ICSI, it can be concluded that there is a high rate of male factor infertility in Latin America. Practitioners are using a more expensive, more invasive procedure to force fertilisation to occur.
- Religion is another axis of oppression that needs highlighting. The Catholic Church's opposition to condoms, contraceptives and abortions has adverse implications for women.
- The 'wantedness' of and desire for children is manifested in and through the ART industry. Here, the issue of class oppression and stratified reproduction comes in; poor women do not get access to technologies they need and want, including ARTs.
- Race is another aspect that was highlighted - IVF doctors who think it is their duty to 'lighten' Ecuador raise up questions of who is valued and who is not.

- Most countries have no laws and their ART industries are unregulated with only voluntary registries.

### ***Renate Klein***

- While unsafe abortion is one of the reasons why we have secondary infertility

in women, there is a need to look into incomplete abortions, particularly in the Global South.

- It is clear that women have not been able to shake off the patriarchal assumption that they are available for sex. With ARTs, are we shifting women from one form of oppression to another, wherein they use technology to stay within patriarchal family structures? Technology cannot be the way out of male oppression.

### Discussion Points

- Given that the political system is constrained by religion to the extent that the Left is also beholden to the dictates of the Church because of the support they received at some point, it is important to trace how religion impacts politics and therefore, governance.
- Kinship is not necessarily a non-communal, pure space that is being polluted by these technologies. Reproduction has always been assisted in different ways. Certainly in Bangladesh, informal adoptions have been common. They are not about the law or Islam, but really about community practice. As long as the public-private distinction is not ruptured, they are allowed and acceptable.
- In discussions of religion, it is important to contextualise the politicisation of religion, rather than viewing religion per se as the problem. Thus, it has been useful to look at the different relationships between the church and the state in different countries of Latin America, rather than seeing the Catholic Church itself as the problem. This is significant because there is a tendency to look at Islam as the explanatory framework when we discuss Muslim societies today. We

need to be vigilant about the way religion is mobilised, depending on particular political formations.

- ARTs are definitely signifiers of modernity in Bangladesh today. While India, with its big technology industry, claims a place at the global high table, the middle classes in Bangladesh can at least say that they have ARTs. Technologies that women need, like paternity tests, need to be given priority. The entry point for the women's movement should be to demystify the relationship between technology, modernity and women's emancipation. Feminists do not need to think of ARTs as *the* most pressing problem, but it has to be placed in a certain context. For a regional map, it would be interesting to see the commonalities and the disjunctures within regions on technology and ARTs, and the reasons behind them.
- One thing that became clear in the course of the research in IVF clinics in Ecuador was the idea of 'reproductive modernity'. There are long histories, beyond Ecuador and Latin America, of making racialised bifurcations between who can reproduce and who cannot. It is the poor and the 'primitive' who are considered very fertile, and although epidemiologically inaccurate, in Ecuador there is a strong association between infertility and upper class women. Therefore, to have an 'unreproductive' body, and to gather the resources to fix it through technology, is most definitely a sign of 'status' and 'whiteness'. This is not to say that the women who are investing in this kind of participation are frivolous; because to be able to enter into private sector medicine means one is treated like a worthwhile human being, in a way that entering into public sector medicine means one is treated like an unworthy human being.



There is a study by the London School of Hygiene and Tropical Medicine in Brazil that shows how poorer women actively strategise to get caesarian sections in public hospitals. The C-section rate all across Latin America is very high, but women in private clinics have a much higher C-section rate (90-95 per cent) while in public hospitals it is much lower (20-25 per cent). These women know that C-sections bring greater resources and more attention from doctors. This is similar to what goes on in accessing IVF. C-section literature for public health organisations that talks about women seeking C-sections in frivolous ways is a mis-characterisation of women who are seeking engagements with their bodies that make them feel like worthy citizens. In this context, 'patient' is the word that people use as a sign of honour, because it engages one in a patron-client relationship.

- The voices and experiences from the women's movement that are countering the hegemony of the private medical sector need to be highlighted. The women's movement has to work with states which have strong governance structures for markets, but weak state structures for people.
- Ecuador has a feminist movement with some organising around issues of reproductive health and sexual rights. However, most of this organising has been around issues like access to the morning after pill. Being able to access any form of birth control has always been incredibly easy. Yet interestingly, the discussion that aimed to make the morning after pill legal is what prompted it becoming illegal, as the Catholic Church harnessed its powers to create a backlash. It is in terms of abortion that the lack of regulation on

the one hand and lack of governance on the other comes into play. Abortion until recently has not been a political issue because so many of the feminists involved in these movements were wealthier or middle class, with access to paid-for, safe abortion. Further, lawyers, IVF doctors, etc. did not want to say anything very specific about reproductive technologies in the Child and Adolescent Civil Code, because that would force the Catholic Church (and others) to take a stand on the question of when life begins. Therefore, even while IVF services are advertised publicly, there is no governance or movement for regulation.

- The women who undergo unsafe abortions are not all the women who undergo IVF. The link between unsafe abortions and infertility needs to be examined, particularly in terms of the incidence and the role of the medical community. Further, we need to distinguish between safe and unsafe abortion when talking of infertility, because abortion is a very important safety net, and the right to safe abortion must be protected. Even the overuse of menstrual regulation pills in the family planning programs of Latin American and South Asia should be discussed as a cause of infertility.
- Although the feminist movement in Brazil has an upper class character, it is a very strong movement, with a history of struggle under the dictatorship, together with the movement for public health reforms. In 1988, Brazil got a new democratic constitution with many inclusions that were important for women, like the right to family planning. However, this was implemented only later for surgical sterilisation in the country.

Ten years after this, in 2006, 40 per cent of all births in Brazil were surgical. There are many reasons for this, not only because of the high amount of money involved, but also because good family planning services are not available and reproductive rights are not addressed adequately. Moreover, the scientists who aligned with Monsanto were in techno-science embryo research, including two women who worked on embryo stem cells and had encountered problems because they had imported embryos from the US. Because of this, the Brazilian state made a law forbidding this kind of import. So there is a lot of scientific 'progressive' interest in doing such research in Brazil.

Further, class is definitely important when we talk about vulnerability. However, in the first research with rich women, it was clear that they also had their limitations with regard to treatment.

- There is a close connection between food, women's health, reproductive health and bio-technology. Bio-technology law is very important as it ties up with other issues of IPR, and the control of

pesticides, pharmaceuticals, etc., by companies like Monsanto and Syngenta. This raises the possibility of building alliances and networking on these issues. With GM, abortion, IVF and high finance, every failure is viewed as a new business opportunity. Today we are confronted with a scenario where a company is happy to put the terminator gene in a seed for profit, and has a clear mandate to control 90 per cent of seeds in the world through IPR. The National Biotechnology Regulatory Authority Act, which is in the process of being finalised, is characterised by an absence of gender and public health concerns.

- The post marketing surveillance of over the counter drugs is supposed to be done by companies, but this is not happening.
- It is clear that big business is stoking the latent desires of women. There is also a certain commerce within the family that is going on in Ecuador where women feel they are free agents doing commerce without any external influence. However, there is big business in the background, whose reality for these women is masked by the idea of transactions and networks free of patriarchy.







## for Movement Building

International Consultation on commercial, economic and ethical aspects of  
Assisted Reproductive Technologies (ARTs)

January 22-24, 2010, New Delhi

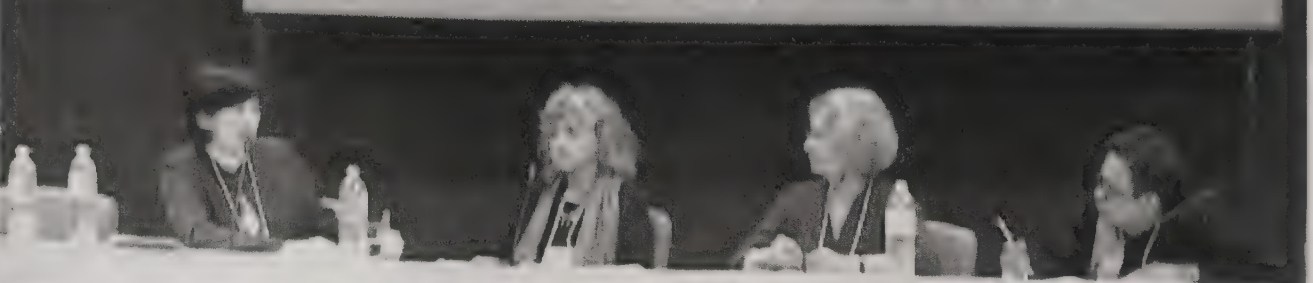
Stama - Resource Group for Women and Health



International Consultation on commercial, economic and ethical aspects of  
Assisted Reproductive Technologies (ARTs)

January 22-24, 2010, New Delhi

Stama - Resource Group for Women and Health















# In Pursuit of Tissues: Global Movement and the Biogenetic Form

Chayanika Shah and Sarah Sexton

## **Our Bodies Ourselves: The Fertility Industry and Threats to Women's Health: Creating a More Coordinated Global Response**

*Judy Norsigian*

A summary of the challenges facing us in ARTs are as follows:

- The increasing demand for women's eggs for both IVF purposes and for use in SCNT or 'cloning research', not just because of infertility but for other social or genetic reasons that are not related to fertility.
- Increasing demand for women as commercial gestational mothers.
- Deflection of attention and resources away from the primary prevention of infertility (e.g. Sexually Transmitted Infections, toxic exposures).
- No adequate safety data for many infertility drugs, especially the class of drugs that suppresses ovulation, while substantial anecdotal evidence of harm grows. There is also growing evidence of harm from ovarian hyperstimulatory drugs (a class of drugs used in IVF).
- The proliferation of misleading advertisements and marketing schemes to increase both the demand and supply.

In the US, as the demand for eggs rises in the fertility setting, it is understandable that payment incentives are also increasing. As scientists seek more eggs for SCNT research, there is increasing pressure to allow for payment incentives in the research arena. This is currently a point of contention in California, where the California Institute of Regenerative Medicine is seeking new rules that would allow for payments that were previously prohibited. A US company (The World Egg Bank) has signed a deal with fertility clinics in Spain to provide US consumers with 'IVF vacations' to Spain. They offer the world's largest online registry of egg donors and specialise in egg extraction services, and the storage and sale of cryopreserved eggs. Since the early nineties, in response to the growth of IVF services globally, the international market for human eggs has increased substantially, as chronicled in Debora Spar's book titled *The Baby Business*. President Diana Thomas notes that "recipients no longer have to synchronise cycles with the donor and the donor can be anywhere in the world."

Newspaper reports of scandals have increased in number, and in one case, the Romanian government prosecuted two Israeli physicians for illegally procuring eggs from young Romanian women. Some of these women are now suing for strange physical problems they believe are related to the egg extraction procedures.



The combination of big capital and an effective global marketing strategy will be difficult to counter, especially in terms of informing women with a more balanced perspective of the risks involved. The lure of big money will continue to draw unethical practitioners to the field. Already a proliferation of advertisements seeking donors with specified physical features can be seen.

The first evidence of a statistically significant increase in the risk of ovarian tumours among IVF patients can also be seen now. In 20 to 33 per cent of the cases, mild Ovarian Hyperstimulation Syndrome (OHSS) is said to exist, while in one per cent of the cases severe OHSS could lead to hospitalisation, renal failure and death, in rare cases.

There have been no long-term studies of Lupron which is being used off-label in IVF clinics. Lupron (leuprolide acetate) is the drug that is most often used to shut down a woman's ovaries, before stimulating them with other drugs to produce multiple follicles. It has caused a range of problems reported to the Food and Drug Administration, including rash, dizziness, chest pain, nausea, depression, amnesia (disturbance in memory), hypertension (high arterial blood pressure), muscular pain, bone pain, liver function abnormality, vision abnormality, anxiety, myasthenia (muscle weakness) and vertigo.

Many of these Lupron-related problems are discussed at greater length on a website created by Lynne Millican, a nurse-practitioner who herself experienced harmful consequences from multiple uses of Lupron. Her work builds upon that of the National Lupron Victims Network (NLVN), founded by two dentist sisters, Linda and Rita Abend (Rita became seriously ill following Lupron use). The NLVN website was mysteriously taken down in 2003.

The recent positions taken in the US, include those by the ASRM (American Society for Reproductive Medicine) which regards infertility as a disease. Similar definitions are being considered by the ESHRE (European Society of Human Reproduction and Embryology), and by the ICMART (International Committee for Monitoring Assisted Reproductive Technologies). A US Supreme Court opinion agreed with a lower court statement that reproduction is a major life activity and confirmed that conditions that interfere with reproduction should be regarded as disabilities, as defined in the Americans with Disabilities Act.

There is very little policy related to ARTs in general in the US. There is no federal regulation of eggs. In terms of state regulation, Indiana prohibits the sale of human eggs and allows for reimbursement for expenses, lost wages, and up to US \$ 3,000 for recovery time. Louisiana explicitly prohibits the sale of human eggs and Virginia explicitly authorises its sale. Voluntary guidelines from American Society for Reproductive Medicine state that women should not be paid more than US \$ 5,000 for eggs, and anything over US \$ 10,000 is 'inappropriate'. Further, women should not undergo more than six cycles of egg retrieval.

In 'Gender and Justice in the Gene Age' a feminist meeting on New Reproductive and Genetic Technologies in May 2004, participants strongly articulated their opposition to – sex selection and disability de-selection, without the support for a law that would make selective abortion illegal; the ideal of perfection of humans and children; the commercialisation of health and commodification of human life, body parts or cells; practices and social conditions that pressure people to select children based on their traits, or to select traits in their children; the development

and proliferation of technologies that select, modify and commodify children.

The strategies and next steps identified included - developing more comprehensive approaches to advocacy on these issues, organising a dialogue between disability and feminist activists, identifying doctors and scientists to join the group's advocacy and counter the claim that it was anti-science; supporting research that would show the impact of high-tech biomedicine on communities in terms of use of resources; creating an international network for information and monitoring; developing a feminist statement on these technologies that could act as a bridge to other social movements; developing popular educational tools and materials to expand understanding of the issues; reaching other communities and constituencies; countering media messages that distort the debate on these technologies; connecting with movements that have long fought eugenics; and building new partnerships.

Persuasive messages around SCNT have to be crafted saying that it is the gateway to genetically-enhanced or modified children and that there is no *safe* way to conduct human germline genetic modification. Studies can be done *ad nauseum* in animal models, but it does not eliminate the huge and ethically unacceptable risks of such studies in humans. In other words, there is no 'safe' way to get 'from here to there.'

In generating a public discourse that can be the foundation for change, 'opinion leaders' or spokespersons with substantial stature to take up one or more of the issues have to be identified. Eventually multiple spokespersons have to be prepared to begin a coordinated media outreach campaign that demonstrates these concerns to be shared by more than a few fringe activists. Appropriate policy

makers have to be approached as political momentum grows and a public mandate for change becomes imperative. Concepts that are generally compelling and already have traction in the public's mind will have to be capitalised on.

Suggested first efforts:

- Since there are 'lunatic' fringe physicians and researchers (e.g. Dr Panos Zavros) and others who are proponents of reproductive cloning, a global ban on human reproductive cloning can be called for, with insistence that countries that have not instituted such a ban, do so now.
- Those who voice opposition are likely to have vested interests in perfecting and using reproductive cloning technology (if not for human reproductive cloning, then possibly for other germline genetic engineering schemes). This effort could bring them out into the open.
- Ways need to be sought to keep the Dr Hwang Woo Suk scandal alive in the mind of the public (Korea Women's Associations United and Korean Womenlink could take a lead role here).
- The expanded use of public dollars for infertility services has to be challenged when infertility prevention measures are not adequately funded.
- New ways have to be sought to challenge the misleading claims and advertisements of the IVF 'industry'. These could include writing booklets for young women (similar to *Egg Donation: the Reasons and the Risks* by Kristi Lew) to counter the misleading hype. They could be put online and used through a range of social networking sites to market them effectively to younger women. Secondly,



copies of the primer, *Human Genetic Engineering* by activist Pete Shanks can be brought into high schools and into the hands of biology teachers. Thirdly, more accurate information about what young women are told can be collected.

- There is a need to raise awareness of the unique ways in which reproductive tourism exploits women and why people in different countries who care about these issues must think of policies and practices outside their own countries.
- The anti-intellectual trends among many politicians must be responded to in different ways.
- Possible research and study areas include systematic surveys of women who pursue the idea of providing their eggs for IVF; exploration of medical, psycho-sociological and ethical implications; consequences of egg donation in European countries, especially in Czech Republic, Spain, United Kingdom, Ukraine and Romania.
- Grants could be utilised from foundations that support the use of documentaries in bringing about needed social change (e.g. The Fledgling Fund in NYC). One possibility is to launch a collaboration that utilises *Made in India* (and/or similar films), to motivate more people to become activists in this cause. University venues can be excellent sites for such movement-building. Films that model attitudes and behaviours that are considered worth supporting (e.g. *My Sister's Keeper*), could be promoted.
- There is a need to adopt different forms – political power (for policy changes); the power of information (reaching people with the truth, hoping that at least some

of them will act to protect themselves and their loved ones).

## Coordinators' Comments

### *Sarah Sexton*

While we discuss the movement across borders of tissues, embryos, companies, doctors and so on, there is also an issue of the non-movement of people in today's age of visa regimes.

### *Chayanika Shah*

Is the egg closer to blood or to an organ? This is a confusing issue, and in our discussions, we seem to be drawing parallels between eggs and organs. This is especially significant if we want to be clearer about why we are opposed to something. What exactly is it about embryo donation or purchase that makes us so uncomfortable? We need to engage with the debate on technology, including the differences of opinion between us on technology. While we may have an ideological position against regulation and these technologies, yet the reality of the 250 clinics in India demands some sort of regulation. At the pragmatic level, where do we draw the line with technology? This is an issue we struggled with in 1989 also. Over the last twenty years our positions have become more difficult, because the line is being pushed further and further, as we had anticipated. If we resist the push, the line will shift slower. How will it be possible, if at all, in a rapidly changing world to make this line not shift at all?

## Discussion Points

- Is it correct to always pose technology as the problem? We need to be nuanced about the kinds of technology that might be problematic, and not say that technology is itself inherently a problem.

We have all embraced technology in a big way. In many ways, to be human is to be technological, because humans use technology. Are technologies then a master's tools, and if they are, then how do we make these technologies ours? There is a distinction, however, between technologies that can be controlled and those that cannot. We need to be critical of technologies that are positioned as the 'saviour'. Attention needs to be paid to the human aspect of technologies. There is a question here of power, of who controls the processes of technological development, and who decides which technologies will be evolved. Further, do technologies have a way of universalising despite differences in local contexts?

- This consultation would have been different with the presence of an additional constituency – women who are interested in obtaining this technology. Are we going to engage with this constituency as a possible future strategy? After all, our formulations of what it is that we are opposing will depend on the consumers of these services. However, this raises the issue that the consumers of these technologies are not monolithic either. Do we want to bring in ten women who had terrible experiences with ARTs, or ten women for whom it was a relatively good experience? Further, men must be engaged in movement-building as well, since without their participation, we will not be successful in our strategies.
- We need to learn from our more recent experience of the administration of the HPV (Human Papilloma Virus) vaccine. In Australia, it is government policy to vaccinate all young girls in schools regularly. There is evidence of 1,200 girls under the age of 16 being included in the initial trials. Girls as young as 9 years were pushed into this three-part vaccination.

It is not a vaccination against cervical cancer, but against two strains of one virus – HPV, when there are many types of cervical cancer that have nothing to do with this virus. In India now, 2 research projects are being coordinated by PATH (a US based NGO), in the states of Gujarat and Andhra Pradesh, involving 32,000 girls. We need to be critical of this vaccine at an international level. The HPV vaccine has had adverse effects on women, and particularly on fertility, as it has been seen that women who took the vaccine when pregnant, suffered miscarriages and delivered disabled fetuses.

- In the US, to get opinion leaders on its side, Merck funded groups of women legislators to promote the idea of mandatory school based vaccinations for young girls. This campaign was very effective, and even got some states to pass laws (which have since been reversed) mandating that all school age girls be given HPV vaccines. There have been debates about whether parents should be allowed to opt-out of HPV and other vaccine programs. There is also a strong anti-vaccine campaign in the US that opposes vaccines of any sort for any reason, which is really like throwing the baby out with the bathwater. In the experience of Our Bodies Ourselves fighting against state level laws, although we were up against huge machinery, the information did eventually get through to legislators. In terms of strategy, we need to get to opinion leaders beforehand, with credible information that cannot be discounted.
- Information about the off label use of drugs is either not being collected, or is unavailable. Off label use of drugs is probably at its greatest right now,



and needs to be researched by the government.

- In the US, the CDC is tracking the offspring of women who get IVF. However, data is being collected on a small scale only and very problematic effects on offspring and women who have undergone IVF themselves are not being tracked longitudinally. The Dutch 15-year study should be commended in this regard. A report (in draft form now) that came out of a CDC symposium (with participation from ASRM and other advocacy groups) is going to be put out that emphasises the primary prevention of infertility, while talking about other issues also. If this report comes through, it will give us a very strong case for looking into the allocation of public funds so that millions are not spent on IVF, with primary prevention of infertility not receiving adequate funds. In 1973, Our Bodies Ourselves organised a talk with the VD (Venereal Disease) division, where a physician, Dr. Paul Weiser, made the point that we are not going to reach the public about VD - mainly gonorrhoea and syphilis - unless we reach women. Basic messages of prevention and protection from exposure during sexual intercourse must reach people. However, prevention in general has never gained much traction in the United States because there is not much money to be made in it.
- While the CDC data is reliable, it is voluntary and not all clinics participate and provide information. Further, it focuses more on success rates, rather than on data on the effects of these drugs on women.
- In questions of whether we are going to use the language of donation, of commerce or of exchange within families, perhaps we need to pay attention to how there is not going to be one language given the different countries that these technologies are operating in. These issues are understood through different frameworks, depending on what is useful to understand with in a particular context. A blanket framework is not going to be effective for all.
- Medical tourism operators in the US (like Planet Hospital in California and ProActive Family Solutions in Florida) are in collaboration with hospitals in India to promote fertility tourism. These establishments have huge set-ups in Mumbai and Chennai, and bring in young girls from the US to India for egg donation, throwing in two weeks of sight-seeing. These agencies are not transparent and do not share details like success rates. We need to develop strategies to engage such agencies both in India and in the US.
- Through emails, we should contribute our ideas about the many different strategies we can employ, and after this is collated, we should each take up an aspect where we would be best suited to work. We also need to engage with academics. We must share our material only with trustworthy individuals, not through a website but through email attachments.

Even with regard to medical tourism practices, our best option is probably to put together powerful information and reach the people who are making these choices.

# Challenges and Strategies: Where do we go from here?

Coordinators: Lakshmi Lingam, Marcy Darnovsky, Amit Sengupta

*The coordinators reiterated that several issues have emerged from the Consultation which needed highlighting, further discussion or action. They put forth the issues that each of them had identified.*

## **Lakshmi Lingam**

- Women do not get the treatment they deserve in the public health system. This untreated infectious base gives rise to infertility which earns them a red carpet welcome into the private sector. Is it possible to consider infertility treatment in the public health sector instead of being against all infertility treatments?
- The causes of infertility need to be addressed immediately, from reproductive and sexual health to those causes that we do not know much about, like toxins, the environment, workplace conditions, and so on.
- The conceptualisation of the family and its link with biological motherhood, technological fixes to have a baby as the solution and the pressure to have a baby at any cost need to be questioned. How do we look at this entire spectrum of issues?
- The earlier strategies, for instance against population control, need to be sharpened. They were not perfect, but there are lessons to be learnt from them especially in the area of coercive policies and reproductive

rights; these are not 'individual' issues but exist within a repressive regime where it is considered that all women should have children.

- How do we go beyond the framework of victimhood and look at the agency of women?
- What are our key problems with surrogacy? While we need to have the global as context, we should have the local as our focus. We cannot be immobilised by global institutions, global markets and global governance structures that might not have spaces for us.

## **Marcy Darnovsky**

- We have some clear points of disagreement between us (e.g. should the genie be put back in the bottle or should we make it a friendlier genie?). Given these differences what can we agree on? To employ the same metaphor, are there genies that we want to keep in the bottle?
- Are there global strategies that already exist in dealing with issues of ART?
- International agreements have to be explored while designing a strategy for ARTs. What are the kinds of collaborations and information sharing that we can initiate at the international level?
- Within the question of regulation we have to look at issues of political education



through the media for the protection of women.

### Amit Sengupta

- We must remember that nomenclature is important. If we find a different name for ARTs that represents our ideology, it would send out a strong message demarcating our position from that of the industry. Can we call it 'Reproductive Technology' for now?
- The industry of reproductive technology and its relationship with the objectives of the research and pharmaceutical industries has to be established.
- How do we view technology, and research itself? Do we oppose it in entirety, or do we oppose how it is controlled and organised?

### Discussion Points

- A position vis-à-vis major *religious groups* needs to be carefully examined. Some critical questions have emerged in this context - should we engage with the interface between religion and technologies, since religion cannot be escaped; shall we say 'no' to such alliances, given our negative experiences, for e.g. vis-a-vis sex selection in India.
- ARTs have entered the *public health* sphere in India, with services being offered in two public hospitals in Delhi - AIIMS (All India Institute of Medical Sciences) and LNJP (Lok Nayak Jai Prakash). Does the logic used to critique the ART industry apply to the public sector too? If not, then there has to be clarity on why we are pressing for infertility treatment in the public sector;

from the perspective of rights and within a non-patriarchal, public health model. It is not adequate to press for it to be offered in the public sector simply because people will otherwise go to the private sector. Should the information available on low cost fertility treatments for resource poor countries (from ESHRE, for instance) be explored further? Or does asking for cheaper infertility treatments imply complicity with the fertility industry?

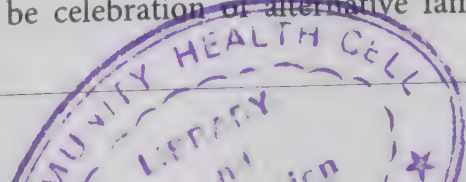
Before moving forward, a position must be clearly established about where we are right now. Are we asking for globalisation, or in this case, commodification, with a human face? It should be remembered that IVF has a public sector beginning in India, after which it flowed into the private sector. It was initiated under the garb of population control, with the rhetoric that if we better understand what causes infertility, we will be better able to control population. In the nineties, the Ministry of Health and Family Welfare decided that infertility was a genuine reproductive health issue that needed addressing. In Army Hospitals, IVF treatment is still provided free of charge for those soldiers whose postings can cause infertility. Nonetheless, the need for quality primary health care needs to be emphasised.

- At the heart of the entire debate on ARTs lie notions of motherhood, fertility and eugenics, promoted by stakeholders in a *patriarchal and heteronormative framework*. It is in this context that service providers are presenting commercial surrogacy as altruistic. We need to create discourses and discussions that normalise infertility. Further, alternative possibilities of constructing families outside of blood/genetic continuity and marriage need to be explored. There has to be celebration of alternative families

WH-105

12704

P10



and the option of not having children. In addition to the psychological and physical pain of infertile women, we need to talk about the social pain of infertility because a lot of women who do not fit within the social normative framework, are not allowed to have children. Glorification of motherhood needs to be challenged.

In the US, a quarter of the adults live in nuclear family formations (with husband, wife and children), a quarter in other types of families – divorced, gay, lesbian, etc., a quarter are married couples living without children and a quarter are single adults living alone. So the nuclear family model of marriage with children is actually the minority; and these other family formations need to be celebrated and talked about. Family fostering in Egypt is one such example.

- The debates with respect to *disability* have to be incorporated within ART-related concerns; the birth of a child with disability, the added vulnerability of disabled women and the reproductive rights of disabled women.
- The *legal and policy framework* for ARTs needs to address a number of areas; ethical issues, family relationships, informed choice, research, gender issues, access to ARTs with regard to class and sexual orientation, embryo status, commercialised reproduction, players involved in ARTs, its control, sale and compensation, role of industry, the relationship between clinics, laboratories and individuals, control and registration of agencies, individuals, or companies across borders, and legal consequences regarding creation of rights and obligations between ART clinics and

persons involved in protecting the child. The effort at influencing policy has to involve a range of Ministries in order to incorporate the range of issues – Health, Family Welfare, Law, Foreign Affairs, Commerce, Women and Child Development, Human Resources, Food and Drug, etc.

- *Corporate misdemeanors* must be documented and highlighted, for instance, Monsanto's successful lobbying that repealed the law banning genetically modified foods in Brazil. There has to be some focus on players like Bayer, Merck, etc. and it has to be considered whether there is a case for a minimum draft to regulate these technologies by harmonising laws across borders? Further, particularly with regard to HPV, the role of pharmaceuticals like Merck must be examined and critiqued. The irresponsibility of medical companies towards human body parts needs to be discussed. We need to get the message out that the players in the biotech, reprotech, finance, pharmaceutical, research and corporate sectors, are all linked. This could increase our allies, for instance, among the ecological, health, feminist and anti-globalisation activists.
- It is important to remember that *technologies* fail, and cannot be depended on wholly. Further, infertility treatments and ARTs are not interchangeable; they must not be confused as the same<sup>10</sup>. Technology is not the answer, and adoption is one option that is beyond technology. A more nuanced critique of technology is required – should it be banned or should it be negotiated to see how it can be used for the benefit of the people who really need it? For some women, technology is

<sup>10</sup> It was clarified by Sama that from the perspective of their research and activism, ARTs are not included within the framework of 'infertility treatment' as they do not treat or cure infertility but merely 'assist' reproduction. Infertility treatments must deal with the underlying causes of infertility such as genital TB, malnutrition, etc.



a way of negotiating with their reality. Since we are claiming to take a stand on behalf of the women who are using these technologies, it is important to bring their voices into this debate. At no point must women be alienated since they are the primary constituency. It is important to view them as part victim and part agent, and to both question and respect their choices. Further, it is important to ask who controls technology. Artificial insemination has been taken away from our hands under the guise of HIV prevention, by disallowing the use of non-frozen sperms. However, it is considered alright to continue to have sex with a husband who may be HIV positive. This is a contradiction. Since ARTs under the present conception include artificial insemination, they should not be rejected entirely.

- At the *international level*, CEDAW could be approached for shadow reports and information could be sought from different countries about their particular situation with regard to ARTs, its regulation, how women's rights are positioned, the public health system's response to ARTs and women's rights, and policies of the government. Perhaps CEDAW could be approached to issue general comments on women's rights, women's health and ARTs with a focus on non-negotiables?
- Engagement with the *media* is essential in the effort to generate awareness and public discussion. Currently, the media bypasses all aspects of ARTs except surrogacy, which is sensationalised. Catchy and clear slogans have to be developed while reaching out in the public domain, just like any good political or marketing campaign, such as 'Merck is murky' or 'Are you a sub-prime embryo?'. There is also a need to understand how

to use social networking and new media (Facebook, blogs, etc.) to get messages across.

- *Adoption* needs to be de-stigmatised and put on the agenda as an alternative to ARTs. Documentation and dissemination of stories about adoption need to be done. In traditional communities (such as Assam) adoption is an option. However, some people are known to have resorted to IVF because of the long waiting periods for adoption. Overall the adoption of girls has been increasing. Society is not static and we need to recognise that family structures are changing in some ways. In the context of adoption laws in India, while Hindu couples can have complete parenthood over their adopted child, other religions can adopt only as legal guardians. Any attempt to homogenise adoption laws is viewed as Hindu-centric, and even if this includes progressive aspects, there is a risk of losing allies from non-Hindu communities. Nonetheless, the government has set up a commission to look into and harmonise adoption laws in India. Further, of the many myths that surround women's bodies, a common and persistent one is that bearing children is key to women's mental and physical fitness. This is propagated by the medical fraternity and mainstream media, films, etc. and must be combated.
- Globally, more than half of all infertility is *male factor Infertility*, most of which is incurable. With our focus on women, we risk losing sight of this. We need a huge public education campaign so we can talk about male infertility more openly, and so the burden of fertility does not fall only on women. Some common cause needs to be made with the men who are facing infertility. A lot of male factor infertility is caused by Non-Gonococcal

Urethritis (NGU), which is preventable by using condoms. The focus on men and preventable male factor infertility could motivate men to use condoms. Further, 50 per cent of male factor infertility is genetic and not preventable. The use of ICSI to overcome male fertility results in the perpetuation of male infertility into future generations. The sons of genetically infertile men will carry that genetic mutation and this presents a huge bioethical issue. Such information needs to be made available, especially given that male infertility gets treated on the female body.

- It is important to track the fate of the *ART Bill*; sometimes such Bills get passed quietly amidst all the noise about more important ones like those on terrorism, army budgets, etc. There is also the danger that even after comments have been submitted on the Bill, the state could deploy this simply as a box-ticking exercise; as evidence that public engagement on the Bill was carried out. Rejecting the Bill in its current form is also an option.
- The close link between ARTs and *research* is disturbing. The fact that there is a lot of discussion and debate on the ethics of research and the need to regulate research could provide an opportunity with ARTs as well. Some of the research areas that we need to look at are: causes of infertility, hazards of ARTs and safety issues, commercialisation – costs, turnovers, etc. and links with research and pharmaceutical industries.
- A desirable position with regard to the *Intellectual Property* status, particularly across borders, needs to be established. We need to be clear that we are against the theft and privatisation of knowledge, the

use of women's bodies by industries as a free commons, the partitioning of bodies and exploitative medicalisation, the latest being public private partnerships whose genuine outcome is profit rather than health.

- We need to think in terms of the 3 *Rs*: Research questions – a lot of issues have come up that require further research; Regulation – which direction are we going in at the international and national levels; and Re-Education – how do we get across the messages that we are clear about?
- A loose global network on New Reproductive Technologies can be established with immediate effect. Not only strategies, but also positions have to be developed, taking into consideration variables such as the rural-urban divide. It is important to establish an ethical charter or a list of non-negotiables and targets in the short run, which are feasible. We could look at using internet laws that ban the advertisement of certain things in countries where they are illegal (e.g. sex selective abortion).
- We need to minimize *health risks* from the market push on present technologies, and the potential risks of new technologies. Safety issues have to be raised while engaging with regulation and policy. Off-label use of drugs has to be opposed strongly because it is unscientific and absolutely at the discretion of doctors.
- The *experiences of women* need to be brought into our discussions – those who have paid money to clinics and not got results, those who are suffering from clinical depression resulting from treatment, etc. As activists, we should begin from the community and be guided by their voices. We have to be



mindful about the right of people to have children, especially people who cannot afford to have children. The context of surrogate women has to be explored further. What is the nature of participation and the stand of the population control committee and the sex selection committee on ARTs?

- We need to make some urgent feminist interventions in medical and science education. The STS (Science, Technology and Society) aspects of science need to be addressed, together with ethics, such as through engagements with feminists within biological sciences.
- Traditional medicine practitioners are also advertising infertility treatments and need to be looked at.
- Nomenclature is indeed an issue ('Assisted Reproductive Technology' or 'Reproductive Technology?'), but we need to continue using the common parlance in order to be understood.
- A detailed mapping of the ART business and conferences is essential, also to establish its linkages with other industries, like food and tourism. We need to scrutinise the claims that this industry is making, such as success rates. For instance, Merck has started a consumer protection outfit for fertility tourism. Additionally, the Tamil Nadu State Tourism Department promotes ARTs as part of its medical tourism package.

## Summary

**Amit Sengupta** summarised the areas of consensus within the group:

- The importance of public health measures located within developed and universally accessible public health systems that prevent and treat infertility.
- Rejection of patriarchy, family and eugenics, and recognition that these form the framework within which ARTs are located and where the so-called 'need' for these technologies is, in fact, created.
- Understanding of how this technology is controlled with intellectual property rights, markets, finance capitalisation and globalisation.

**Lakshmi Lingam** highlighted some key points from the discussion:

- It is important to engage with legal frameworks in different countries, for example, the draft ART Bill in India.
- The 'Goliath', as it were, must be taken on in bits and pieces, from the perspective of strategising.
- Cross-movement conversations and links with other people's movements are necessary. One way would be to prepare a note in various languages that can be disseminated across the country.
- Minority groups at the ground-level must be engaged with. There is silence on how Muslim women cope with infertility.

# The Way Forward

NB Sarojini

In the previous consultation organised by Sama, the Bill (Draft Assisted Reproductive Technology (Regulation) Bill and Rules - 2008) was discussed and a common press release emerged demanding that the ICMR and the MOHFW (Ministry of Health and Family Welfare) put up the draft Bill on their websites and invite comments on it, have a larger discussion both at regional levels and at the national level with different movements, individuals, researchers, health activists, providers, users and civil society organisations and bring in all the concerns raised, which are pro-women and protect women's rights and health concerns.

Sama tried to critique the Bill in detail and many participants of the current consultation did so too, independently. Everybody sent their critique to the ICMR and to the Ministry, but there is no information on how many issues from the Bill have been looked into. A representative of the Ministry said that the Bill was already with the Law Commission, perhaps implying that it has been finalised by the MOHFW. There is no way of knowing whether the concerns raised have been incorporated because the Bill, in its final form, was not shared with anybody, including those who submitted their comments.

The concern is that the Bill has been developed mainly by IVF providers and not by the people who are engaged with the issue from the ethics movement, women's movement or public health movement. The Law Commission came up with its own report

on surrogacy, which reinforces patriarchal values, emphasises biological motherhood and says 'no' to commercial surrogacy, whereas the Bill promotes commercial surrogacy. Given this contradiction, it is unclear where we stand at the moment. In this context, this consultation was an opportunity to review the situation regarding ART policy in other countries, in an attempt to formulate responses and strategies at the local, regional and global levels. Although the advancement of these technologies and the related discourses are at different stages in different countries, it is important to compare and learn from each other's experiences.

Several issues, as well as several differences, have emerged; even within India, there are different positions on surrogacy, on technologies, on choices and on rights. There is a need for continued alertness, preparedness, information sharing and strategising. Therefore, it is crucial to have a platform where we can continue to discuss and debate the commercial, economic and ethical aspects of Assisted Reproductive Technologies. A *small group* has to be set up to take this issue forward, and it should include even those who could not be present at this consultation. We hope that this process of coming together and working together will yield concrete results. We hope to continue to engage with one other, through consultations and otherwise, so these debates can reach out to other activists within the social sector, academia, as well as the medical and legal fraternity.

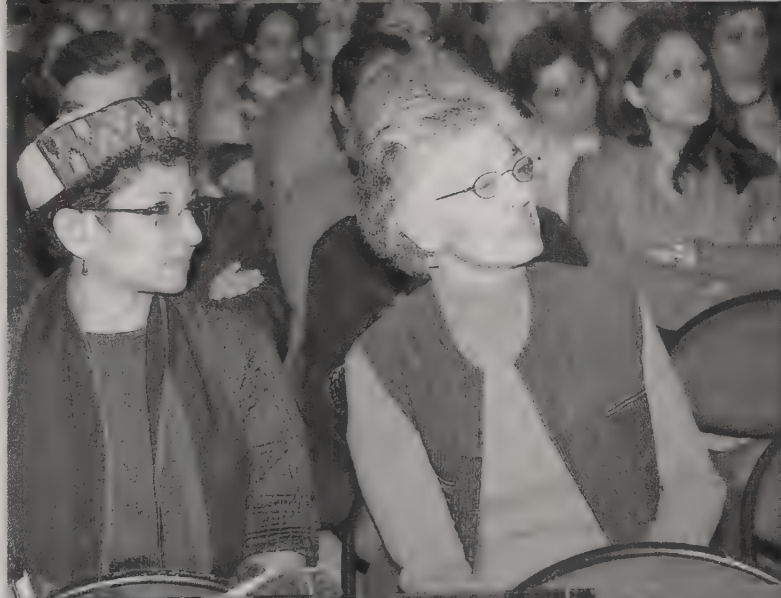












# Programme

---

## **Day 1: 22nd January 2010**

### **The Consultation in Perspective**

*Anjali and Aastha from Sama and Pramada Menon*

Context of Assisted Reproductive Technologies

Objectives of the Consultation

### **Key Note Address: The Gene Express: Speeding Toward What Future?**

*Betsy Hartmann*

## **Session 1**

### **Biogenetic Transactions: Politics and Economics**

*Coordinators: Manisha Gupte and Judy Norsigian*

Technology, Markets and the Commoditisation of Life

*Amit Sengupta*

Biogenetic Futures: Patents and Property, Speculation and Services

*Sarah Sexton*

## **Session 2**

### **Global Experiences: Asia Pacific**

*Coordinators: Mohan Rao and Shree Mulay*

From the Cutting Edge to 'Business as Usual': What does the future hold for women in Australia's mainstreaming of ARTs?

*Renate Klein*

Assisted Reproductive Technologies at the Crossroads: Neoliberal Economy, National Depopulation Crisis and the Politics of Reproduction in South Korea

*Young-Gyung Paik*



### Session 3

#### **Global Experiences: South Asia**

*Coordinators: Imrana Qadeer and Farida Akhter*

Medecins Sans Frontiers. This day and This way!  
*Nighat Khan*

Assisted Reproductive Technologies in Nepal: A Brief Picture  
*Pinky Singh Rana*

### Session 4

#### **Emerging Perspectives and Challenges: Towards a Global Movement**

*Coordinators: Sandhya Srinivasan and Jyotsna Agnihotri Gupta*

### **Day 2: 23rd January 2010**

### Session 5

#### **Global Experiences: South Asia**

*Coordinators: Padmini Swaminathan and Betsy Hartmann*

'Doctor's Babies': The Scenario of Unregulated Trade over Infertility in Bangladesh  
*Farida Akhter*

Unraveling the Fertility Industry: ARTs in the Indian Context  
*NB Sarojini*

Experimental State, State of Experiments: State, Science, Citizens and Embryonic Stem  
Cell Research in India  
*Aditya Bharadwaj*

### Session 6

#### **Global Experiences: Middle East and Israel**

*Coordinators: Malini Bhattacharya and Aditya Bharadwaj*

Ova Donation Bill: The Israeli Case  
*Hedva Eyal*

Globalisation and Gametes: Reproductive Tourism, Islamic Bioethics and Middle  
Eastern Modernity  
*Marcia C Inhorn*

## Session 7

### **Global Experiences: US, Canada and The Netherlands**

*Coordinators: Amar Jesani and Sarah Hodges*

Commercialisation of Reproductive and Genetic Technologies: What Lessons for Biotech Developments around the Globe?

*Marcy Darnovsky*

Closing the Barn Door after the Horse has Bolted: Canadian Experience with Regulating Assisted Human Reproduction

*Shree Mulay*

Bio-crossings and the Global Fertility Market

*Jyotsna Agnihotri Gupta*

## Session 8

### **Emerging Perspectives and Challenges: Towards a Global Movement**

*Coordinators: Renu Khanna and Young-Gyung Paik*

## **Day 3: 24th January 2010**

## Session 9

### **Global Experiences: Latin America**

*Coordinators: Renate Klein and Marcia Inhorn*

Egg Traffic in Ecuador in the Context of Latin American Reproductive Policy

*Elizabeth Roberts*

Assisted Reproductive Technologies in Brazil: An Overview of the Scenario and its Ethical, Legal and Social Challenges

*Marilena Correa*

## Session 10

### **In Pursuit of Tissues: Global Movement and the Biogenetic Form**

*Chayanika Shah and Sarah Sexton*

Our Bodies Ourselves: The Fertility Industry and Threats to Women's Health: Creating a More Coordinated Global Response

*Judy Norsigian*

## Session 11

### **Challenges and Strategies: Where do we go from here?**

*Coordinators: Lakshmi Lingam, Marcy Darnovsky, Amit Sengupta*

### **The Way Forward**

*NB Sarojini*



## About Sama

---

Sama is a resource group working on issues of women's health and rights, which seeks to locate the concerns of women's well being in the larger context of socio-historical, economic and political realities. Sama considers health a fundamental human right and believes that the provision of quality and affordable health care to every citizen is the responsibility of the state.

Sama believes that equality and empowerment can be ensured only when poverty, curtailment of capabilities, lack of livelihood rights, lack of health services and access to health care, illiteracy and multiple forms of discrimination based on caste, class, gender, religion, ethnicity, sexual orientation and many other rubrics are structurally challenged. Our commitment is to integrate the gender, caste, class and rights

analysis within the wider context of other social relations in order to emphasise the complexity of existing power relations that work towards exclusion and marginalisation.

Sama engages with Community Based Organisations, Non Government Organisations, women's groups and collectives, health networks and coalitions, autonomous bodies like the National Human Rights Commission (NHRC) and National Commission for Women (NCW), youth, traditional healers and birth attendants, health care providers, medical professionals and the media. The word Sama means equality in Sanskrit, Hindustani and other Indian languages. The logo symbolises balance and equality. These are an intrinsic part of Sama's philosophy and vision.

## Speakers' and coordinators' profiles

---

**Aastha Sharma** works with Sama - Resource Group for Women and Health as a project associate. She holds a Bachelors degree in Journalism and a Masters in Social Work from University of Delhi. She is currently working on ARTs through research, policy advocacy, capacity building and material development and is involved with the Right to Health Campaign, as part of Sama. Previously, she worked as a social work trainee at AIIMS hospital and Project Concern International/India and did a research project with UNICEF India on girls' education.

**Dr Aditya Bharadwaj** is a lecturer in the School of Social and Political Science, University of Edinburgh. His principal research interest is in the global spread of new reproductive, genetic, and stem cell bio-technologies. Aditya has published extensively on these subjects and has co-authored the monograph *Risky Relations: Family, Kinship and the New Genetics* (Berg, 2006). He is the lead author of *Local Cells, Global Science: The Proliferation of Stem Cell Technologies in India* (Routledge, 2009) and is currently completing the research monograph *Conceptions: Infertility and Procreative Modernity in India* (Berghahn Books, 2010).

**Dr Amar Jesani** is managing trustee of Anusandhan Trust, which manages three institutions - CEHAT (Centre for Enquiry into Health and Allied Themes) and CSER (Centre for Studies in Ethics and Rights) in Mumbai and SATHI (Support for Advocacy and Training to Health Initiatives) in Pune.

He is also one of the founders of the Forum for Medical Ethics Society and its journal, *Indian Journal of Medical Ethics* and is presently on its editorial board. He was national coordinator of the two National Bioethics Conferences (2005 and 2007) of the *IJME*. He is on the national faculty of the ICMR for its NIH supported research bioethics training programme and a visiting faculty teaching bioethics at five institutions in India.

**Dr Amit Sengupta** is associated with the Delhi Science Forum, a public interest organisation working on science and technology policy issues. He is trained in medicine, and works on issues related to public health, pharmaceutical policy, IPR and other science and technology issues. He is the secretary of the All India People's Science Network and is member of the international secretariat of the World Social Forum. He is currently the joint convener of Jan Swasthya Abhiyan.

**Anjali Sheno**i, a Masters graduate in International Development from the University of Bath, UK, is currently working with Sama - Resource Group for Women and Health. She has been engaged with Sama's research on ARTs and has also actively contributed to advocacy initiatives around the regulation of ARTs in India.

**Dr Betsy Hartmann** is the director of the Population and Development Program and professor of Development Studies at Hampshire College in Amherst, MA, USA (<http://www.BetsyHartmann>).



com). A longstanding activist in the international women's health movement, she writes and speaks frequently on the intersections between reproductive rights, population, immi-gration, environment and security concerns in activist, policy and scholarly venues. She is a prolific writer with many non-fiction books and two political thrillers to her name.

**Chayanika** is an activist in the women's movement and part of FAOW (Forum Against Oppression of Women) and LABIA (Lesbians And Bisexuals In Action) in Mumbai. She has been working on concerns pertaining to sexuality rights and has also co-authored *We and our fertility*, a book looking into the entire range of reproductive technologies from the point of view that there is no fundamental difference between two kinds (contraceptive and conceptive) of technologies.

**Dr Elizabeth Roberts** is assistant professor, Department of Anthropology, University of Michigan. Her work over the years has focused on issues of reproduction, citizenship, IVF, governance in Latin America and the Caribbean with a lot of research and scholarly work focused on Ecuador. She has written prolifically and organised conferences and presented papers globally on these issues. She has professional membership of a number of Anthropological Societies and is on the Science, Technology, Medicine Interest Group of the American Anthropology Association.

**Farida Akhter** is the executive director of UBINIG (Policy Research for Development Alternative) in Bangladesh ([www.ubinig.org](http://www.ubinig.org)). She has been active in the national level women's movement in Bangladesh since 1985. Farida is a council member of Asian Women's Human Rights Council, is involved actively with FINRRAGE (Feminist International Network for Resistance Against Reproductive and Genetic Engineering),

and is a member of Resistance Network, a network of various women's organisations working on issues of women's health. She is a prolific writer in Bengali and English and has a number of publications and research papers to her credit.

**Hedva Eyal** is the coordinator of the Women and Medical Technologies project of Isha L'Isha, Israel. She has worked as the general coordinator of the Haifa Feminist Center from 2004 until January 2009. She holds a BA in Philosophy, an MA in the History of Art, is a graduate of the Heschell Center's Social and Environmental Leadership programme, and a PhD candidate at the Hebrew University in Jerusalem. Her research is on the issue of regulation and health in Israel at the School for Public Policy and Government.

**Dr Imrana Qadeer** is currently senior fellow at the Centre for Women's Development Studies in New Delhi. She has taught Public Health at the Jawaharlal Nehru University in New Delhi for 35 years. She is a member of the Standing Committee of the University Grants Commission on Women's Studies Centres. Her main interests are organisation of health services, political economy of health, epidemiology, research methodology, and women's health. She has written extensively on issues of women's health.

**Judy Norsigian** is executive director of Our Bodies Ourselves, co-author of *Our Bodies, Ourselves* (8th edition, May 2005) and a member of the editorial teams for *Our Bodies, Ourselves: Menopause* (2006) and *Our Bodies, Ourselves: Pregnancy and Birth* (2008). She speaks and writes frequently on a wide range of women's health concerns, including abortion and contraception, sexually transmissible infections, genetics and reproductive technologies, body image, tobacco and women, women and health care

reform, and midwifery advocacy. She has appeared on numerous national television and radio programs and currently serves as a board member for Public Responsibility in Medicine and Research.

**Dr Jyotsna Agnihotri Gupta** is currently senior lecturer in Gender and Diversity at the University for Humanistics in Utrecht, and affiliated fellow at the International Institute of Asian Studies, Leiden University, in the Netherlands. She is the author of *New Reproductive Technologies, Women's Health and Autonomy: Freedom or Dependency?* (Sage, 2000) and several articles published in books and scientific journals on population and development issues, new reproductive technologies, including genetics, women's health and autonomy, and bioethics, based on empirical research in India and the Netherlands. Since 2007 she is a member of the board of Feminist Approaches to Bioethics.

**Dr Lakshmi Lingam** is a professor in the Centre for Women's Studies at the Tata Institute for Social Sciences, Mumbai, India. In 2004-05, as a FullBright/New Century scholar, she worked on the program titled 'Global Empowerment of Women'. She was also a visiting scholar at the Centre for Education of Women, University of Michigan, Ann Arbor (2003), a resource person at the International Training Program of Uppsala University, Sweden (2000-02) and the Institute of Social Studies, the Hague, Netherlands (2002). She is a curriculum advisory board member of several women's studies departments in Indian universities as well as technical and ethical advisory board member of NGOs. She has also contributed to gender and equity mainstreaming activities of government departments in a number of states in India.

**Dr Malini Bhattacharya** was the former director of the School of Women's Studies

and a professor in Jadavpur University in Kolkata. She has been a member of Parliament and a member of the National Commission for Women. She is currently a member of State Planning Board, West Bengal, Vice-Chairperson of Folk and Tribal Cultural Centre, West Bengal and member of West Bengal State Commission for Women.

**Manisha Gupte** is a veteran of the women's movement in India, and has been involved with issues related to health, sexuality, reproductive rights, human rights and violence for over 30 years. Manisha is the founder trustee and co-convener of MASUM (Mahila Sarvangeen Utkarsh Mandal) and managing trustee of Medico Friend Circle. She was co-ordinator for the 10<sup>th</sup> International Women and Health Meeting, held in Delhi in 2005, and has also been a visiting scholar at Johns Hopkins University, USA and senior research officer at CEHAT and FRCH. She has worked with the government of Maharashtra, Planning Commission, National Commission for Women and NRHM on policy issues. She is the recipient of several awards and citations, including the 'Diwaliben Mehta Award' for long-term commitment to social issues, given by the former president of India R Venkatraman.

**Dr Marcia C Inhorn** is the William K Lanman Jr Professor of Anthropology and International Affairs in the Department of Anthropology and The Whitney and Betty MacMillan Center for International and Area Studies at Yale University. A specialist on Middle Eastern gender and health issues, Marcia has conducted research on the social impact of infertility and assisted reproductive technologies in Egypt, Lebanon, the United Arab Emirates, and Arab America over the past 20 years. She has published extensively and is the founding editor of *JMEWS (Journal of Middle East Women's Studies)* of the Association of Middle East Women's Studies,



and co-editor of the Berghahn Book series on *Fertility, Sexuality and Reproduction*.

**Dr Marcy Darnovsky** is associate executive director at the Center for Genetics and Society ([www.genetics-and-society.org](http://www.genetics-and-society.org)), a Berkeley, California-based public affairs organisation working to encourage responsible uses and effective societal governance of reproductive and genetic biotechnologies. She speaks and writes widely on human bio-technologies, focusing on their social justice, human rights, health equity, and public interest implications. She has appeared on national television and radio, and been cited in hundreds of news and magazine articles. Her PhD is from the History of Consciousness program at the University of California, Santa Cruz.

**Dr Marilena Correa** is lecturer at the Social Medicine Institute of the State University of Rio de Janeiro. She is a public health specialist (National School of Public Health of the Oswaldo Cruz Foundation, 1985). She holds a Masters in Public Health (1992) and a PhD in Humanities and Health Sciences (1997) from the State University of Rio de Janeiro. During her doctorate she had a scholarship from the Brazilian Council for Scientific and Technological Development for a 16-months programme on medical sociology at the Ecole des Hautes Etudes en Sciences Sociales, in Paris. She is member of the Brazilian Association of Public Health (Abrasco), Brazilian Association of Bioethics (SBB); International Sociological Association (ISA); Feminist Approaches to Bioethics Network (FaB); and the International Association of Bioethics (IAB).

**Dr Mohan Rao** is professor at the Centre of Social Medicine and Community Health, School of Social Sciences, Jawaharlal Nehru University, New Delhi. A medical doctor specialised in public health, he has written

extensively on health and population policy and on the history and politics of health and family planning. He is the author of *From Population Control to Reproductive Health: Malthusian Arithmetic* (Sage, 2004) and has edited *Disinvesting in Health: The World Bank's Health Prescriptions* (Sage, 1999) and *The Unheard Scream: Reproductive Health and Women's Lives in India* (Zubaan/Kali for Women, 2004). His new volume, co-edited with Sarah Sexton entitled *Markets and Malthus: Gender, Population and Health in Neoliberal Times* (Sage) is forthcoming. He has been a member of the National Population Commission and is actively involved with the Jan Swasthya Abhiyan.

**Dr Nighat Khan** runs the Fertility Advisory Center in Karachi. She is also affiliated with the Department of Bioethics, Aga Khan University, Karachi for many years. She received her primary medical degree in Pakistan and completed her PhD in Reproductive Biology in England. She has worked as a postdoctoral clinical scientist in the Assisted Reproductive Unit at Kings College, London and also at the Center for Human Reproduction in Chicago, USA.

**Dr Padmini Swaminathan** is professor and Reserve Bank of India Chair in Regional Economics at the Madras Institute of Development Studies, Chennai, Tamil Nadu, India. Padmini's work provides a multi-disciplinary focus to her research interests that now cover and explore the linkages between the themes of industrial organisation, labour, education and health – all from a gender perspective. She actively serves on the editorial boards of several academic journals and also does work for provincial and central government bodies such as the Tamil Nadu State Statistical Committee, the High Court of Madras, the Central Planning Commission, to name a few.

**Pinky Singh Rana** did her Masters in Political Science, and has been involved in the development sector since 1994, with particular focus on conceptualisation, design and implementation of development programmes on sexual and gender based violence, reproductive health, malnutrition, trafficking and women's employment. She has worked extensively in Western Nepal, one of the poorest regions of the country. She is associated with the Safe Motherhood Network, and is currently with SAATHI, Nepal.

**Pramada Menon** is a queer, feminist activist and an independent consultant working on issues of sexuality, sexual rights, gender, violence against women, organisational development and livelihoods for more than two decades. She is the co-founder of CREA, an international women's human rights organisation and worked as the Director Programs of the organisation from 2000 – 2008. Before co-founding CREA, she was the executive director of Dastkar, an organisation working to ensure sustainable livelihoods for craftspeople. She has been very active in the sexual rights movement in India and internationally. She is also a stand up performance artist and does a show 'Fat, Feminist and Free', which examines issues of gender, sexuality, sexual rights and body image through a series of humorous stories based on her life.

**Dr Renate Klein** holds an MSc from Zürich University, a BA (Honours) in Women's Studies from the University of California at Berkeley and a PhD in Sociology of Education from the University of London. She is a founding member of FINRRAGE (Feminist International Network of Resistance to Reproductive and Genetic Engineering) and CATWA (The Coalition against Trafficking in Women, Australia). Until August 2006 she

was associate professor in Women's Studies at Deakin University, Melbourne, Australia where she developed and taught an MA course in Reproductive Medicine and Feminist Ethics. She has also written extensively on reproductive technologies.

**Renu Khanna** is a feminist activist and the founder trustee of SAHAJ (Society for Health Alternatives). She has over 25 years of experience in gender and health care management and in training various levels of health care and social development professionals and para-professionals. She is engaged in the application of behavioural sciences to organisations and the institutional development of voluntary and more recently public sector organisations. She is part of several interdisciplinary groups working on women's health and rights issues and has co-edited and co-ordinated the publication of several books like *Women, Healing and Plants* by Shodhini and *Towards Comprehensive Women's Health Programmes and Policy*, a volume of papers written by eminent researchers and activists.

**Sandhya Srinivasan** is a freelance journalist and consultant. She writes on health and development for various publications and websites, and was a Panos Reproductive Health Media Fellow in 1998, writing on the infertility industry in India. She is consulting editor, public health, for the development website [www.infochangeindia.org](http://www.infochangeindia.org) and commissioning editor for [www.hivaidsonline.in](http://www.hivaidsonline.in), both managed by the Centre for Communication and Development Studies. Sandhya is executive editor of the Indian Journal of Medical Ethics, member of the editorial board of Developing World Bioethics, and member of the faculty of the Centre for Studies in Ethics and Rights. In 2002, she was awarded the Ashoka Fellowship for her work in medical ethics.



**Dr Sarah Hodges** is associate professor in the Department of History, University of Warwick, UK. She is author of *Contraception, Colonialism and Commerce: Birth Control in South India, 1920-1940* (2008), editor of *Reproductive Health in India: History, Politics, Controversies* (2006) and co-editor of the 2009 *Women's Studies Quarterly* Special Issue on Technologies. She is currently spending a sabbatical year in Chennai, working on her current project, 'Biotrash: Medical Garbage, Bodily Economies and the Making of New Chennai.' This project investigates the commoditisation of health under neoliberalism by tracing the economic afterlives of items routinely discarded in clinical encounters, such as disposable syringes and umbilical cord blood.

**Sarah Sexton** works with The Corner House, a non-profit research and solidarity group based in the United Kingdom, which focuses on a wide range of environmental and social justice issues. In the past few years, she has written and edited several books and articles on various intersections between health, genetic and reproductive technologies, trade, population thinking, foreign investment and refugee issues.

**NB Sarojini** has been working on women's health and rights for many years and is the director of Sama - Resource Group for Women and Health. She is involved in the coordination of a national level research on reproductive technologies and their implications on women. She has co-authored 'Women's Right to Health', published by the National Human Rights Commission, contributed to the Political Science Textbook for class VII by the National Council of Educational Research and Training, and co-authored a book, *Touch me, Touch me not: Women, Plants and Healing* (Kali for Women, 1997). She is also the joint convenor of Jan

Swasthya Abhiyan, and the ex convenor of Medico Friend Circle. She co-coordinated the MFC fact finding committee that studied the health impact of the Gujarat riots of 2002 and contributed to the report, 'Carnage in Gujarat: A Public Health Crisis'.

**Dr Shree Mulay** is the associate dean of the Community Health and Humanities Division in the Faculty of Medicine at Memorial University of Newfoundland, Canada. She is the former director of the McGill Centre for Research and Teaching on Women (1996-2007). Shree's more recent research has focused on women's health; one such research done with Dr Navsharan Singh on *Informed Consent and Contraceptive Trials: Implications for Human Rights of Women* investigated the experiences of women with non-surgical sterilisation method and their understanding of informed consent. Shree has published about 70 peer-reviewed scientific papers, several reviews and chapters in books. She has also written several op-ed pieces for newspapers and magazines and on refugees and immigrants and women's health and new reproductive technologies.

**Dr Young-Gyung Paik** is affiliated with the Program in History and Philosophy of Science at Seoul National University, as a post doctoral fellow for the research team for the Education of Human Resources in Science, Technology, Society and Culture. Her PhD in Anthropology from Johns Hopkins University, Baltimore, USA was on *Technologies of 'the Korean Family': Population Crisis and the Politics of Reproduction in Contemporary South Korea*. Young-Gyung also teaches courses on ethics, culture and bio-technology at Korea Advanced Institute of Science and Technology (KAIST) and has served as a coordinator of the International Forum on Biotechnology and Human Rights of Women, hosted by the Korean WomenLink in 2006.

## Participants

1. **Aastha Sharma**  
Sama - Resource Group for Women and Health  
B- 45 Main Road Shivalik  
Malviya Nagar  
New Delhi  
Phone: 011 – 26692730/65637632  
Email: sama.womenshealth@gmail.com
2. **Abha Bhaiya**  
Jagori Grameen  
Sidhbari Rakkar Road  
District Kangra  
Himachal Pradesh 176057  
Phone: 01892-246857  
Email: info@jagorigrameen.org
3. **Aditya Bharadwaj**  
School of Social & Political Science  
University of Edinburgh  
6.24 Chrystal Macmillan Building  
15A George Square  
Edinburgh EH8 9LD  
Scotland, United Kingdom  
Phone: + (0) 131 651 3861  
Email: adi.bharadwaj@ed.ac.uk
4. **Ajitha S.George**  
Omon Mahila Sangathan  
Village - Duccasai  
P.O Noamundi, Chaibasa  
West Singhbhum-833217  
Jharkhand  
Phone: 06582-256416/256159  
Email: ajithasg@gmail.com
5. **Amar Jesani**  
Indian Journal of Medical Ethics  
Trustee, Anusandhan Trust  
Sai Ashray, Aaram Society Road  
Vakola, Santacruz East  
Mumbai 400055  
Phone: 022- 2666 1176  
Email: amar.jesani@gmail.com
6. **Amit Sengupta**  
Delhi Science Forum  
D-158, Lower Ground Floor  
Saket  
New Delhi-110017  
Phone: 011-26862716, 26524342  
Email: ctdds@vsnl.com
7. **Anchita Ghatak**  
Kolkata  
Mobile: +91-98303-26101  
Email: anchita.ghatak@gmail.com
8. **Anjali Sheno**  
Sama - Resource Group for Women and Health  
B- 45 Main Road Shivalik  
Malviya Nagar  
New Delhi  
Phone: 011 – 26692730/65637632  
Email: sama.womenshealth@gmail.com
9. **Antony Kurian**  
Sama- Resource Group for Women and Health  
B- 45 Main Road Shivalik  
Malviya Nagar  
New Delhi  
Phone: 011 – 26692730/65637632  
Email: sama.womenshealth@gmail.com
10. **Anu Gupta**  
Eklavya  
33 Saket Nagar  
Dewas 455001  
Madhya Pradesh  
Phone: 07272 – 223496  
Email: anuarvindbali@gmail.com
11. **Arathi P.M.**  
Centre for Social Medicine and Community Health  
School of Social Sciences  
Jawaharlal Nehru University  
New Delhi- 110067  
Mobile: 91-98684-13141  
Email: arathipm@gmail.com



12. **Ashok Yadav**  
Sama- Resource Group for Women and Health  
B- 45 Main Road Shivalik  
Malviya Nagar  
New Delhi  
Phone: 011 – 26692730/65637632  
Email: sama.womenshealth@gmail.com
13. **Atul Sood**  
Centre for the Study of Regional Development  
Jawaharlal Nehru University  
New Delhi- 110067  
Phone: 26704573/26704463  
Email: atulsood61@gmail.com, atulsood@mail.jnu.ac.in
14. **Beenu Rawat**  
Sama- Resource Group for Women and Health  
B- 45 Main Road Shivalik  
Malviya Nagar  
New Delhi  
Phone: 011 – 26692730/65637632  
Email: sama.womenshealth@gmail.com
15. **Betsy Hartmann**  
CLPP, Hampshire College  
Amherst, MA 01002.  
USA  
Phone: 413-559-6046  
Email: bhartmann@hampshire.edu
16. **Bhawna Rawat**  
Sama- Resource Group for Women and Health  
B- 45 Main Road Shivalik  
Malviya Nagar  
New Delhi  
Phone: 011 – 26692730/65637632  
Email: sama.womenshealth@gmail.com
17. **Bijoya Roy**  
Centre for Women and Development Studies  
25, Bhai Vir Singh Marg  
Gol Market  
New Delhi- 110001  
Phone: 011- 23366930, 23345530, 23365541  
Email: bijoya@cwds.ac.in, bijoyaroy@gmail.com
18. **Chayanika Shah**  
Forum Against Oppression of Women  
19, Bhatia Bhavan  
Babrekar Marg  
Dadar (West)  
Mumbai- 400028  
Phone: 022- 24010482  
Email: chayanikashah@gmail.com
19. **Chandana Anusha**  
Student  
University of Delhi  
Mobile: 9810231995  
Email: chandana.anusha@gmail.com
20. **Daisy Dharmaraj**  
TEST Foundation  
4 Sathalvar Street, Mugappair West  
Chennai 600037  
Tamil Nadu  
Phone: 044-26244211/26244100  
Email: daisy.dharmaraj@gmail.com
21. **Deepa Venkatachalam**  
Sama- Resource Group for Women and Health  
B- 45 Main Road Shivalik  
Malviya Nagar  
New Delhi  
Phone: 011 – 26692730/65637632  
Email: sama.womenshealth@gmail.com
22. **Dharashree Das**  
Simon Fraser University  
515 West Hastings Street  
Vancouver, B.C.  
Canada V6B 5K3  
Phone: 778.782.5000  
Email: dharashree30@rediffmail.com, dharashreedas@yahoo.co.in
23. **Dina Siddiqi**  
Center For Gender, Sexuality and HIV/AIDS  
James P. Grant School of Public Health  
BRAC University  
66 Mohakhali  
Dhaka 1212  
Bangladesh.  
Phone: +88 (02) 8824051-4 (PABX) (Information Desk ext. 4003), +88 (02) 8853948-9  
Email: dmsiddiqi@yahoo.com

24. **Elizabeth F. S. Roberts**  
University of Michigan  
Department of Anthropology  
The Residential College  
108 West Hall  
1085 South University Avenue  
Ann Arbor, USA  
Phone: 734-936-0642  
Email: lfsrob@umich.edu
25. **Farida Akhter**  
UBINIG,  
22/13 Khiljee Road, Block-B  
Mohammedpur  
Dhaka-1207  
Bangladesh.  
Phone: 880-2-8111465 / 8116420  
Email: kachuripana@gmail.com
26. **Hedva Eyal**  
Coordinator  
Women and Medical Technologies  
Isha L'Isha- Haifa Feminist Center  
118 Arlozorov  
St.Haifa 33276  
Israel  
Phone :+972 4 865 0977 or +972 4 866 0951  
Email: wmt.isha@gmail.com  
Website: www.isha.org.il
27. **Imrana Qadeer**  
C-4/111, Safdarjung Development Area  
New Delhi- 110016  
Phone: 011- 26510824  
Email: imranaqadeer@gmail.com
28. **Indu Agnihotri**  
Centre for Women and Development Studies  
25, Bhai Vir Singh Marg  
Gol Market  
New Delhi- 110001  
Phone: 011-23365541, 23345530  
Email: indu@cwds.ac.in
29. **Janaki**  
J 291 1st Floor  
Saket  
New Delhi  
Phone: 011- 29551384
30. **Jashodhara Das Gupta**  
SAHAYOG  
C-153, Golf View Apartments  
Saket  
New Delhi-110017  
Phone: 011-2685 1101  
Email: jashodhara@sahayogindia.org
31. **Jaya Sagade**  
ILS Law College  
Law College Road  
Pune- 411004  
Maharashtra  
Mobile: +91-9890003149  
Email: sagade@gmail.com
32. **Jayeeta Chowdhury**  
Mumbai  
Phone: 022-42155431  
Email: jayeetachowdhury@gmail.com,  
jaye\_ch9@yahoo.com
33. **Jennifer Liang**  
The Action Northeast Trust  
Udangshri Dera  
Rowmari, via Bongaigaon  
Distt CHIRANG (BTAD)  
Assam 783380  
Phone: 03664 293802 / 293803  
Email: jenniferliang07@gmail.com
34. **Judy Norsigian**  
Our Bodies Ourselves  
5 Upland Rd, Suite 3  
Cambridge, MA 02140  
USA  
Phone: 617-245-0200 x11  
Email: judy@bwhbc.org
35. **Jyotsna Agnihotri Gupta**  
Gender and Diversity  
University for Humanistics  
Utrecht  
The Netherlands  
Email: jagupta@tiscali.nl
36. **Kamla Bhasin**  
Sangat  
B-114 Shivalik, Malviya Nagar  
New Delhi 110 017  
Phone: 011 - 2669 1219, 2669 1220  
Email: kamlabhasin@gmail.com,  
kamla@sangatsouthasia.org



37. **Kiran Ambwani**  
Ministry of Health and Family Welfare Government  
of India  
Family Planning Section  
Nirmaan Bhawan  
New Delhi  
Telex: 231-65413
38. **Kranti**  
Vasant View A wing, flat 201  
D'Monte Lane  
Malad (West)  
Mumbai  
Phone: 022-28886237  
Email: krantijean@gmail.com
39. **Lakshmi Lingam**  
Centre for Women's Studies  
Tata Institute of Social Sciences  
Deonar  
Mumbai- 400088  
Phone: 022- 25525311  
Email: lakshmi.lingam@gmail.com
40. **Malini Bhattacharya**  
West Bengal Commission for Women  
Kolkata  
Email: mihirmalini@gmail.com,  
wbcw@vsnl.net
41. **Manisha Gupte**  
MASUM  
B-1, Flat No. 41-44  
Kubera Vihar, Gadital,  
Hadapsar  
Pune -411 028  
Maharashtra  
Phone: 020- 26995625/33  
Email: manishagupte@gmail.com
42. **Manjeer Mukherjee**  
Lonavala  
India  
Mobile: +91-9637821728  
Email: contactmanjeer@gmail.com
43. **Marcia C. Inhorn**  
Yale University, Department of Anthropology  
10 Sachem Street  
P.O. Box 208277  
New Haven, CT 06520-8277  
USA  
Phone: 203-432-4510  
Email: marcia.inhorn@yale.edu
44. **Marcy Darnovsky**  
Center for Genetics and Society  
1936 University Avenue, Suite 350  
Berkeley, CA 94704  
USA  
Phone: 510-625-0819 ext 305  
Email: mdarnovsky@geneticsandsociety.org
45. **Marilena C. D. V. Correa**  
The Social Medicine Institute  
State University of Rio de Janeiro  
Brazil  
Phone: +5521 22252853, 86691957  
Email: mcorrea@ism.com.br
46. **Mira Shiva**  
Institute for Health Equity and Society/AIDAN/  
IPHC/Diverse Women for Diversity (South Asia)  
A-60, Hauz Khas  
New Delhi- 100014  
Phone: 011-25612385  
Email: mirashiva@yahoo.com
47. **Mohan Rao**  
Centre of Social Medicine and Community Health  
Jawaharlal Nehru University  
New Delhi – 110067  
Phone: 011-2674-2730  
Email: mohanrao2008@gmail.com
48. **Mohana Chaterjee**  
SAHAYOG  
Delhi  
Mobile: 91-9873719291  
Email: mohana@sahyogindia.org
49. **Morissa Zuckerman**  
Student  
USA

50. **Navsharan Singh**  
International Development Research Centre  
208 Jorbagh  
New Delhi-110003  
Phone: 011-24619411  
Email: rbaksh@idrc.ca, nsingh@idrc.org.in
51. **Neha Madhiwalla**  
Centre for Studies in Ethics and Rights Indian Journal  
of Medical Ethics  
501, Dalkhanian House, B Wing  
Behind State Bank of India  
Nehru Road, Vakola Pipe Line  
Santacruz (East)  
Mumbai – 400 055  
Phone: 022 - 2668 1568  
Email: nmadhiwala@gmail.com
52. **Nighat Khan**  
C/o Dr. Murad M Khan  
Dept of Psychiatry  
Aga Khan University  
Stadium Rd, PO box 3500  
Karachi-74800  
Pakistan  
Phone: 92-21-34934294, 92-21-34932095  
Email: nighatkhan21@hotmail.com
53. **Nilangi**  
SATHI-CEHAT  
Flat no 3-4, Aman E Terrace  
Dahanukar Colony, Kothrud  
Pune 411038  
Maharashtra  
Phone: 020-25452325, 25451413  
Email: nilangi\_nanal@yahoo.com
54. **Padmini Swaminathan**  
Madras Institute of Development Studies  
79, 2nd Main Road, Gandhinagar, Adyar  
Chennai 600 020  
Phone: 044-2-4412295/4412589  
Email: pads78@yahoo.com
55. **Pakhi De**  
J 291 1st Floor  
Saket  
New Delhi  
Phone: 011- 29551384  
Email: pakhi2001@gmail.com,
56. **Pallavi Sobti-Rajpal**  
Utthan  
36, Chitrakut Twins  
B/h Management Enclave  
Nehru Park, Vastrapur  
Ahmedabad  
Gujarat 380015  
Phone: 079 - 26751023, 26732926  
Email: pallavisr@gmail.com, utthan.ahmedabad@gmail.com
57. **Pinky Singh Rana**  
SAATHI Nepal  
Ekantakuna, Lalitpur,  
Kathmandu  
Nepal  
Phone: 00977-9841-20-1897  
Email: pinky\_s\_rana@hotmail.com
58. **Prabha Nagaraja**  
Talking About Reproductive and Sexual Health Issues  
A 91 Amritpuri, 1st Floor  
(Opposite ISKCON Temple)  
East of Kailash  
New Delhi - 110 065  
Phone: 011- 26474022/ 011- 26474023  
Email: tarshi@vsnl.com,  
prabha@tarshi.net
59. **Prabhakar Shreshtha**  
Center for Research on Environment Health and  
Population Activities  
Kusunti Lalitpur  
PO Box 9626  
Kathmandu  
Nepal  
Email: prabhakar@crehpa.org.np
60. **Pramada Menon**  
C-81, Sushant Apartment  
Sushant Lok, Phase -1  
Gurgaon- 122001  
Haryana  
Mobile: 9810215148  
Email: pramadam@gmail.com
61. **Preeti Nayak**  
Sama- Resource Group for Women and Health  
B- 45 Main Road Shivalik  
Malviya Nagar  
New Delhi  
Phone: 011 – 26692730/65637632  
Email: sama.womenshealth@gmail.com



62. **Priya Ranjan**  
Centre for Social Medicine and Community Health  
School of Social Sciences  
Jawaharlal Nehru University  
New Delhi- 110067  
Mobile: 91-995884-3320  
Email: priyaranjanmuni@gmail.com
63. **Priya Suman**  
Student  
University of Pune  
Email: priyasuman@hotmail.com
64. **Radhika Chandiramani**  
Talking About Reproductive and Sexual Health Issues  
A 91 Amritpuri, 1st Floor  
(Opposite ISKCON Temple)  
East of Kailash  
New Delhi -110 065  
Phone: 011- 26474022/ 011- 26474023  
Email: tarshi@vsnl.com
65. **Rajashri Dasgupta**  
218 B lake Terrace Extension  
Calcutta 700029  
West Bengal  
Phone: 033-24661759/6060  
Email: rajashridasgupta@gmail.com  
Rajashri\_dasgupta@yahoo.com
66. **Rajesh K**  
Centre for Studies in Science Policy  
School of Social Sciences  
Jawaharlal Nehru University  
New Delhi- 110067  
Mobile: +91-98999-33487  
Email: rajesh.wdr@gmail.com
67. **Ramesh Awasthi**  
MASUM  
B-1, Flat No. 41-44  
Kubera Vihar, Gadital  
Hadapsar  
Pune -411 028  
Maharashtra  
Phone: 020-26995625/33  
Email: rameshawasthi@gmail.com
68. **Ramila Bisht**  
Centre of Social Medicine and Community Health  
Jawaharlal Nehru University  
New Delhi- 110067  
Mobile: 91- 9868-270702  
Email: ramila.bisht@gmail.com
69. **Ranjan De**  
Magic Lantern Foundation  
J 1881 Basement  
Chittaranjan Park  
New Delhi 110019  
Phone: 011 41605239, 26273244  
Email: ednajnar@gmail.com
70. **Renate Klein**  
PO BOX 920  
North Melbourne  
Victoria 3051  
Australia  
Phone: +61438002979  
Email: rklein@netspace.net.au
71. **Renu Khanna**  
SAHAJ  
1, Tejas Apartment  
53 Haribhakti Colony  
Old Padra Road  
Baroda- 390007  
Gujarat  
Phone: 0265-2340223 /2333438  
Email: sahajbrc@icenet.co.in
72. **Renuka Mukadam**  
Sama- Resource Group for Women and Health  
B- 45 Main Road Shivalik  
Malaviya Nagar  
New Delhi  
Phone: 011 – 26692730/65637632  
Email: sama.womenshealth@gmail.com
73. **Ritwik De**  
J 291 1st Floor  
Saket  
New Delhi  
Phone: 011- 29551384  
Email: ritzokoe@hotmail.com

74. **Rukmini Datta**  
2E 301 Great Eastern Links  
Ram Mandir Road  
Goregaon (W)  
Mumbai- 400104  
Mobile: +91-98203 83366  
Email: rukmini.datta@gmail.com
75. **Rukmini Sen**  
Centre for Women's Development Studies  
25, Bhai Vir Singh Marg  
Gol Market  
New Delhi- 110001  
Mobile: 91-901350 – 3666  
Email: senrukmini18@gmail.com
76. **Sabala**  
Forum Against Oppression of Women  
Vasant View A wing, Flat 201  
D'Monte Lane, Malad (West)  
Mumbai  
Phone: 022-28886237  
Email: sabalsing@gmail.com
77. **Salai Selvam**  
5/640 Bharatipuram, Karupayurani  
Madurai - 20  
Tamil Nadu  
Mobile: +91-944-388-1701  
Email: saalaiselvam@gmail.com
78. **Sandhya Srinivasan**  
8 Seadoll  
54, Chimbai Road  
Bandra (West)  
Mumbai-400050  
Phone: 022-26400607  
Email: sandhya@bom3.vsnl.net.in
79. **Sarah Hodges**  
History Department  
University of Warwick  
Coventry CV4 7AL  
United Kingdom  
C/o MIDS, Chennai  
Phone: +44 2476 523451  
Email: s.hodges@warwick.ac.uk
80. **Sarah Sexton**  
The Corner House  
Station Road  
Sturminster Newton  
Dorset DT101 YJ  
United Kingdom  
Phone: 44 (0) 1258 473795  
Email: sarahsexton@gn.apc.org
81. **NB Sarojini**  
Sama- Resource Group for Women and Health  
B- 45 Main Road Shivalik  
Malviya Nagar  
New Delhi  
Phone: 011 – 26692730/65637632  
Email: sama.womenshealth@gmail.com
82. **Satish Kumar Singh**  
MASVAW, CHSJ  
D-63 Basement  
Saket  
New Delhi – 110017  
Phone: 011 – 40517478, 26111425  
Email: chsj@chsj.org,  
satish@sahayogindia.org
83. **Shalini Singh**  
CREA  
7 Mathura Road, 2nd Floor  
Jangpura B  
New Delhi – 110014  
Phone: 011 2437770724378701 (Extn. 19)  
Email: ssingh@creaworld.org
84. **Shalini Yog**  
Programme Coordinator  
Heinrich Boll Foundation  
C-20, First Floor, Qutub Institutional Area  
New Delhi – 110016  
Phone: 011- 2685 4405, 2651 6695  
Email: shalini.yog@hbfasia.org
85. **Shree Mulay**  
Associate Dean and Professor  
Community Health and Humanities Division  
Faculty of Medicine  
Room 2843, Health Sciences Centre  
300 Prince Philip Drive  
St. John's NL A1B 3V6  
Canada  
Phone : 709-777-8939  
Email: shree.mulay@med.mun.ca



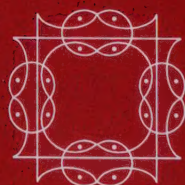
86. **Smitha**  
Jawaharlal Nehru University  
New Delhi- 110067  
Mobile: 91-97177-40701  
Email: smitha.sps@gmail.com
87. **Sneha Mishra**  
AAINA  
N-6/298, Jaydev Vihar  
Bhubaneswar- 751015  
Orissa  
Phone: 0674-2550100  
Email: aaina50@hotmail.com
88. **Sonvi Kapoor**  
International Centre for Research on Women  
C – 139 Defence Colony  
New Delhi – 110024  
Phone: 011-2465-4216  
Email: info.india@icrw.org, skapoor@icrw.org
89. **Sonya Gill**  
AIDWA  
Mumbai  
Mobile: +91-9869250126  
Email: gill.sonya1@gmail.com
90. **Sreekala**  
JN Borooah Lane  
Jorpulchuli  
Guwahati -1  
Assam  
Phone: 0361- 2631582  
Email: sreekala@northeastnetwork.org
91. **S Srinivasan**  
Low Cost Standard Therapeutics  
Ist floor, Premanand Sahitya Sabha  
Dandia Bazar  
Baroda- 390001  
Gujarat  
Phone: 0265-2413319  
Email: sahajbrc@youtele.com  
locostbrd@satyam.net.in
92. **B Subha Sri**  
Reproductive Health Clinic  
Rural Women's Social Education Centre  
Tamil Nadu  
Mobile: +91-9840-260-715  
Email: subhasrib@gmail.com
93. **Suneeta Dhar**  
JAGORI  
B-114, Shivalik  
Malviya Nagar  
New Delhi – 110017  
Phone: 011 2669 1219/20  
Email: jagori@jagori.org  
suneeta.dhar@gmail.com
94. **Susan Hawthorne**  
Victoria University  
PO Box 920  
North Melbourne  
Victoria- 3051  
Australia  
Phone: 61418506645  
Email: hawsu@spinifexpress.com.au
95. **Susheela D Singh**  
Sama- Resource Group for Women and Health  
B- 45 Main Road Shivalik  
Malviya Nagar  
New Delhi  
Phone: 011 – 26692730/65637632  
Email: sama.womenshealth@gmail.com
96. **Svetha Venkataram**  
Sama- Resource Group for Women and Health  
B- 45 Main Road Shivalik  
Malviya Nagar,  
New Delhi  
Phone: 011 – 26692730/65637632  
Email: sama.womenshealth@gmail.com
97. **Vaishali Sinha**  
Independent Filmmaker  
USA  
Mobile: 347 623 2076  
Email: sinha.vaishali@gmail.com
98. **Varada Madge**  
Jawaharlal Nehru University  
New Delhi- 110067  
Mobile: 9818923950  
Email: v\_madge@rediffmail.com
99. **Vasudha Mohanka**  
NARI  
Pune  
Maharashtra  
Mobile: +91-937-020-4378  
Email: vasudha.mohanka@gmail.com

100. **Vineeta Bal**  
Saheli Women's Resource Centre  
Above Unit 105-108  
Defence Colony Flyover Market  
New Delhi 100 024  
Email: vineetabal@yahoo.com
101. **Vrinda Marwah**  
Sama- Resource Group for Women and Health  
B- 45 Main Road Shivalik  
Malviya Nagar  
New Delhi  
Phone: 011 – 26692730/65637632  
Email: sama.womenshealth@gmail.com
102. **Yamini Mishra**  
Centre for Budget and Governance Accountability  
Second Floor, A-11 Niti Bagh  
New Delhi-110 049  
Phone: 011-417 412 85/86/87  
Email: yamini.mishra@gmail.com
103. **Young Gyung Paik**  
Korean WomenLink  
3F Naru, 249-10  
Seongsan-dong, Mapo-gu  
Seoul 121-847  
Korea  
Phone: + 821034755624  
Email: yg.paik@gmail.com





Sama is a Delhi based resource group working on issues of women's rights and health. Sama seeks to locate the concerns of women's health in the context of socio-historical, economic and political realities, and find linkages between women's well being and livelihoods, food, violence and other larger issues that affect their lives. Sama has been working closely with community based organisations, health networks, people's movements, women's groups and health care providers across the country, primarily through building capacities, action research and advocacy.



# Sama

---

Resource Group for Women and Health